Title: The self-management of chronic conditions and the experience of cyber-victimisation in the United Kingdom

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The Self-Management of Chronic Conditions and the Experience of Cyber-Victimisation in the United Kingdom

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Author's Declaration

I, Zhraa Azhr Alhaboby, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research: [The self-management of chronic conditions and the Experience of Cyber-victimisation in the United-Kingdom]

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3. Where I have cited the published work of others, this is always clearly attributed;
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Abstract

Background The victimisation of people with chronic conditions and disabilities has physical, mental and psychosocial consequences. Although this victimisation is documented, victims usually struggle to get the proper support. Research focusing on cyber-victimisation of people with long-term conditions is limited and lacks qualitative elements.

Aims This study aimed to understand the impact of cyber-victimisation among individuals living with chronic conditions in the UK.

Methods A mixed-method design was adopted using a mixed-method online survey, followed by in-depth interviews with victims. The participants were encouraged to share their voices as experts in their own experiences. This was supported by short interviews with general practitioners (GPs) as the gatekeepers to the health system and one of the supportive channels available to victims. A systematic review was completed and published, which helped to identify gaps in the literature. Primary data was collected from 55 victim support groups, patient-support groups, and via social media. The challenges in recruiting victims for this sensitive topic were identified and published to guide future research. The theoretical framework underpinning the study incorporated the Biographical Disruption model, Self-Management and Social Support.

Results Quantitative data from 152 participants showed that almost one in every two people with chronic conditions was cyber-victimised (45.39%). In total, 76.81% of victims had a self-reported disability, and the relationship between cyber-victimisation and disability was statistically significant. Furthermore, 61.11% of victims reported that experiencing cyber-victimisation had affected their self-management plan. The highest impact was on lifestyle changes such as exercise, diet, avoiding triggers, and avoiding excessive smoking or alcohol drinking. This was followed by changes to medications and follow up with healthcare

professionals. Indeed, 69% of victims perceived a worsened self-efficacy scale for health condition self-management following cyber-victimisation. In general, formal support was rated poor, with only 24.53% of victims having spoken to their GPs with variable responses. Six themes emerged from the qualitative data: Biomedical Events (overall health - physical complaints), Impact on Mental Health (psychological and psychiatric effects - helplessness), Multi-level Impact (existing vulnerability - disruption and reprioritisation), The Impact of Complexity (complex situation - struggle for support), Social Network Involvement (social isolation and victim blaming - controversial social support - misrepresentation of self), and Disability Discrimination (inclusion, culture and hate – tax and disability benefits). The participating GPs thought that cyber-victimisation had both mental and physical impact on people with chronic conditions, with concerns over online health forums use. GPs' responses were influenced by individual variations.

Conclusion Cyber-victimisation against people with chronic conditions is prevalent. It is a traumatic event that was introduced after the biographical disruption and working to cope with long-term conditions. It triggered significant fear, had a devastating impact and depleted victims of social support. The impact was multifaceted, and the results from the survey and interviews were convergent. They were also confirmed by the GPs' input. The outcomes provided an in-depth understanding of the impact of cyber-victimisation on such marginalised groups. To initiate change, the results were summarised in a health promotion design that was informed by the participants and gatekeepers, and improved for dissemination. Further context-specific, condition-specific, participatory, and multidisciplinary work are indicated.

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"I like to think that the moon is there even if I am not looking at it"

Albert Einstein

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The sun and the moon, are always there …

List of outputs

Publications

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Relevant contributions

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List of Abbreviations

AIDS	Acquired immunodeficiency syndrome
ADHD	Attention deficit hyperactivity disorder
BMA	British Medical Association
CDC	Centers for Disease Control
CMCD	Centre for Managing Chronic Disease
COPD	Chronic obstructive pulmonary disease
CP	Cerebral palsy
CPS	Crown Prosecution Service
EA	Equality Act
EDS	Ehler Danlos Syndrome
GAD	Generalised anxiety disorder
GP	General practitioner
HbA1c	Glycated haemoglobin
HIV	The human immunodeficiency virus
IBD	Inflammatory bowel disease
IBS	Irritable bowel syndrome
ICD	International Statistical Classification of Diseases and Related Health Problems
ME	Myalgic Encephalomyelitis
MS	Multiple sclerosis
NCD	Non-communicable diseases
ODI	Office for Disability Issues
ONS	Office for National Statistics

POTS	Postural orthostatic tachycardia syndrome
PTSD	Post-traumatic stress disorder
RA	Rheumatoid arthritis

Chapter 1

Introduction

1.1 Rationale

Chronic conditions are prevalent (Alwan, 2011), and the victimisation of people with chronic conditions is a well-documented phenomenon (Blake et al., 2012; Fridh, Lindström and Rosvall, 2015; Fridh et al., 2017). Victimisation could be described as a repeated negative behaviour or attention over time by an individual or a group towards the 'victim' (Kouwenberg et al., 2012). This issue is important because of: 1) the global burden of long-term conditions, their relationship to disabilities and self-management, 2) the existing evidence of discrimination against specific groups, 3) the impact of victimisation, 4) electronic communication, its use in health support and the emergence of cyber-victimisation, and 5) the theoretical impact of cyber-victimisation and the lack of support and in-depth research. Each of these points will be further explained below.

Firstly, millions of people are living with chronic conditions globally, resulting in 35 million mortalities and this is projected to increase (World Health Organization, 2014; Alwan, 2011). In the UK, individuals with long-term conditions comprise 30% of the population, 64% of outpatient appointments, and 70% of inpatients (World Health Organization, 2015; Department of Health and Social Care, 2012). Examples of chronic conditions include hypertension, asthma, diabetes, chronic obstructive pulmonary disease (COPD), depression, and epilepsy. There are less common categories of chronic conditions that also require a management plan such as autoimmune and gastrointestinal diseases (Alwan, 2011). Chronic conditions overlap largely with disabilities in causes, definition and long-term impact, hence it is common to address them together in research (Annerbäck, Sahlqvist and Wingren, 2014). In the UK, a total of 11 million people meet the definition of disability under the Equality Act

2010 (Office for Disability Issues, 2014a; Equality Act 2010), which defines disability as a 'physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities' (Equality Act 2010, p.7). The self-management plan of each chronic condition is different, and it varies between individuals themselves. It generally includes lifestyle and behavioural changes with or without medications (Newman, Steed and Mulligan, 2004). The self-management of chronic conditions was evidenced to be the most effective intervention to improve health outcomes of long-term conditions (Norris, Engelgau and Narayan, 2001). However, this only happens with good adherence to this plan.

Secondly, targeting people with chronic conditions or disabilities is documented in several countries. In Canada, individuals with epilepsy were victimised in schools compared to 'healthy' children or young people living with chronic kidney disease (Hamiwka et al., 2009). Sentenac et al. (2011b) compared victimisation of 12,048 students aged 11, 13, and 14 years old between Ireland and France. They found that children living with chronic conditions, such as diabetes, arthritis, cerebral palsy and allergies, were frequently victimised by their peers, with a prevalence of 20.6% in Ireland and 16.6% in France (Sentenac et al., 2011b). Other documented targeted conditions include attention deficit hyperactivity disorder (ADHD) (Taylor et al., 2010), autism (Chen and Schwartz, 2012), hearing impairment or deafness (Kouwenberg et al., 2012), or chronic tic disorders (Zinner et al., 2012). The underlying causes were 'being different' (Horowitz et al., 2004), poor social skills and having intellectual disabilities (Kowalski and Fedina, 2011) or having a different lifestyle as part of self-management in conditions like diabetes and asthma (Sentenac et al., 2011a). Some cases go beyond hostile words or actions to extremely harmful situations in what is known as 'disability hate crimes' (Quarmby, 2011). The motivation of offenders in disability hate crimes was investigated in a UK-based survey, with 89% of respondents identifying themselves as having disabilities and 87.2% experiencing harassment (Quarmby, 2015). The motivation of offenders

ranged between hate, jealousy and accusations of fraud because of the relative invisibility of some conditions.

Thirdly, electronic communication has become part of everyday life, such as emails, phone messages, social networking (including Facebook, twitter, instagram, YouTube and others). People with chronic conditions have started using online communication for socialisation, health support as well as other online services (Algtewi, Owens and Baker, 2015). Indeed, online management was found to be as effective as face to face support (Lorig et al., 2006). Despite these benefits, such means became easy and available tools for offenders, resulting in what is termed as 'cyber-victimisation'.

Examples of cyber-victimisation include: cyber-harassment (Fridh, Lindström and Rosvall, 2015), intimidation of the target using electronic means of communication; cyberstalking (Short et al., 2015b; Maple, Short and Brown, 2011; Reyns, Henson and Fisher, 2012; Dreßing et al., 2014), which is characterised by fixation, repetitive unwanted contact using online communication that results in fear and distress (Maple, Short and Brown, 2011; Reyns, Henson and Fisher, 2012; Dreßing et al., 2014) cyberbullying (Zych, Ortega-Ruiz and Del Rey, 2015), which resembles stalking and harassment in many aspects, the term is common among young victims and involves direct or indirect hostile actions that are repeated, cause distress and with power differences between the offender and the victim (Sentenac et al., 2011b). Thus, cyberbullying could occur in, but is not limited to schools and workplaces too (Einarsen and Nielsen, 2015; Farley et al., 2015). Online sexual exploitation is another documented form of cyber-victimisation (Mishna, McLuckie and Saini, 2009). These cyber-victimisation types are potentially more devastating than face-to-face methods because of the anonymity of offenders and the availability of a broad range of means for such victimisation. Moreover, most online comments are permanent and the effect does not go away by avoiding a physical presence in a specific context (Anderson, Bresnahan and Musatics, 2014). In fact,

cyber-victimisation leads to international cross-border offences where the offenders are overseas (Sheridan and Grant, 2007), unlike face-to-face victimisation.

Fourthly, the general impact of traditional victimisation on health includes short and long-term consequences on wellbeing, psychological complications such as low self-esteem, anxiety and depression (Hugh-Jones and Smith, 1999; Sheridan and Grant, 2007), physical health complaints (Sentenac et al., 2013), exacerbation of illness (Zinner et al., 2012), disruption of health management (Sentenac et al., 2011a) or the risk of developing a chronic condition (Davis, Coker and Sanderson, 2002). Although the management plan varies between conditions and individuals themselves (Newman, Steed and Mulligan, 2004), being at an increased risk of victimisation (Blake et al., 2012) makes it alarming to impose the above complications on people with long-term conditions. Furthermore, it is documented that cyber-victimisation also has a negative impact on victims' wellbeing (Dreßing et al., 2014), with physical, psychological, social and financial consequences, which in turn, contribute to changes in the quality of life and the health status of victims (Maple, Short and Brown, 2011). It was reported by the National Stalking Helpline (NSH) in the UK that 67% of people who experience cyberstalking develop post-traumatic stress disorder (PTSD) symptoms, and 35% of them had full blown PTSD (National Stalking Helpline, 2015).

Fifthly, the distress resulting from cyber-victimisation can potentially disturb the management of people with chronic conditions. From a biomedical point of view, stress results in hormonal changes which are beneficial in the short term, but in the long-term, which is the case in cyber-victimisation, they negatively affect patients (Bennett, Rodrigues and Klein, 2013; Lukaschek et al., 2013; Pinel, 2011). From a psychosocial point of view, this distress can result in further changes, such as social isolation and influencing the victim's behaviour. Such changes include ignoring exercise or healthy eating, or going for unhealthy behaviour, for example, smoking or excessive drinking, all of which have a distinctive impact on the management of chronic conditions (Sentenac et al., 2011b). Furthermore, victims may face

overwhelming social and mental consequences, but the qualitative research to address how victims have coped with the situation in their own words is limited (Mishna, McLuckie and Saini, 2009). Additionally, despite the potential impact, victims of online abuse struggle for support and experience an incoherent referral system between police, GPs and charity organisations (Appendix 24). Although the role of these channels is well acknowledged as helping professions, for example, the role of GPs as a first point of referral in the health system, the support provided to help victims is generally poor (Galeazzi et al., 2009; Kamphuis et al., 2005). This is possibly due to the lack of experience or awareness about the impact and seriousness of cyber-victimisation.

In summary, the rationale for conducting this study is that millions of people live with chronic conditions, requiring adherence to a self-management plan. The victimisation of people with long-term conditions occurs and the growth of electronic communication has further reshaped this phenomenon. Subsequently, this victimisation has a potentially severe impact on 'victims', disrupting their health management and resulting in devastating complications, with relatively poor support. Research focusing on cyber-victimisation and its effects on people with chronic conditions is limited, with a lack of qualitative elements. In order to determine the magnitude and understand the experiences of cyber-victimisation among people living with chronic conditions, further research is needed for better self-management, increasing awareness and reshaping the response to support patients/victims.

1.2 Research question, aims and objectives

1.2.1 Research Question

What is the impact of the experience of cyber-victimisation on the self-management of chronic conditions among people living with long-term conditions in the UK?

1.2.2 Aims

- To explore the impact of cyber-victimisation on the self-management of chronic conditions among people living with long-term conditions in the UK.
- To employ the results for health promotion to increase the awareness of the effects of cyber-victimisation on people with chronic conditions.

1.2.3 Objectives

Objective 1: To scope the extent and effects of cyber-victimisation among people living with chronic conditions in the UK.

Objective 2: To explore the impact of the experience of cyber-victimisation on self-management of chronic conditions from a patient's/victim's perspective.

Objective 3: To ascertain GPs' experiences and understanding of the effects of cyber-victimisation on patients living with chronic conditions.

1.3 Scope and significance of the study

This study is multifaceted, initiating a new area of research by linking the medical impact with victimisation, psychology and public health literature. The study comprises a literature review, methodology, results and implications for practice. It is anticipated that each step in this research will have its own novel contribution to current knowledge and the significance of this research has been demonstrated by its dissemination in peer reviewed publications (Appendix 4).

The contribution of the literature review is manifested by connecting several disciplines and pioneering a new area of work. The ***systematic review*** (section 2.4) helped in synthesising, expanding, and organising knowledge. It introduced the research area, providing the supportive background for this work, and highlighted potential future work on cyber abuse from a medical perspective that incorporates victims' voices. It also helped to communicate this emerging area to professionals in the field via the publication in a high impact peer reviewed journal (section 6.3).

The ***methodology*** employed online methods throughout this research by contacting 84 online gatekeepers, arranging interviews or using online platforms. The reflections on the challenges of using such methodology with people with disabling long-term conditions was discussed from the perspective of the Social Identity Theory, and was published in a peer reviewed journal (section 3.6). This publication contributed to the knowledge through highlighting positive aspects of online identity observed with victimised people having chronic conditions. This paper helped in giving further recommendations to guide the methodology of future research and provided suggestions to promote inclusivity of marginalised groups in research. These groups were 'traditionally' oppressed due to their disabilities or social isolation secondary to victimisation.

The significance of the study ***results*** can summarised in five main points. Firstly, the significant contribution to *medical knowledge* through looking at the detailed impact of cyber-victimisation on specific chronic conditions. The literature reviewed these patients as a homogenous group which overlooked the specific management and complications in each case, subsequently having inefficient support. Hence, formulating this understanding will contribute to reshaping health services provided to this group and prevent avoidable complications that may harm the lives of the patients, their families/carers and the health system. Secondly, it contributes to evidence based medicine practice by giving voices to a marginalised group. Evidence based medicine is informed by research and is proved to be effective in managing chronic conditions. There is increasing acknowledgement of the narrative side of patient stories in informing evidence based medicine, which has been recently approved by the WHO (Greenhalgh, 2016). However, people with chronic conditions who are victims of cyber-victimisation are marginalised in research, which denies their input into evidence based practice. Hence, empowering these victims through the phenomenological inductive approach in this research helps in providing an in-depth understanding of their experiences and uses these narratives to inform medical practice, specifically primary healthcare.

Thirdly, improving the first response and referral system to improve support provided to patients/victims. Previous work (Appendix 24) indicated the victim's struggle to get proper support. This research addressed instrumental support channels, through interviewing GPs and collaborating with supportive groups. The GP is acknowledged as the first point of contact with the health system and the starting point for referrals, while the police is the authority that can take further actions to stop the harassment. The input from GPs was helpful in improving support and providing further recommendations for both victims and supportive organisations.

Fourthly, ***health promotion***. Further to the referral system, the findings helped in health promotion design that was disseminated through patient and victim support groups. This was

helpful as an early stage of recognition of this issue, which highlighted risk of health deterioration, aimed to improve awareness on such experiences, and initiate change for a longer term by involving patient and victim support groups.

Fifthly, the dissemination of the research findings is anticipated to enlighten the professional community and improve public awareness. The study findings are being continuously shared via publications in peer reviewed journals and conferences. This knowledge sharing approach has contributed to cross-border collaborations and exchange of knowledge with researchers in Sweden (section 3.6), United States (section 2.2.4) and the UK (section 6.3). This research has also contributed to increasing public awareness on the impact of cyber-victimisation on people at risk; this is manifested by media interest in following up the recruitment progress and final results (section 6.3).

1.4 Thesis overview

Chapter 1: The first chapter introduces the rationale of this study, providing brief descriptions of definitions and methods, and the impact of each section on research and practice.

Chapter 2: The second chapter is a review of the literature, providing a supportive background to highlight the gaps in knowledge related to the self-management of chronic conditions, the impact of victimisation, and support. The theoretical framework underpinning this study is also discussed in chapter two.

Chapter 3: The third chapter discusses the study design, philosophical stance, and provides the details of the quantitative and qualitative elements of the work. It also discusses the challenges faced at the recruitment stage.

Chapter 4: The fourth chapter presents the findings from the survey, followed by qualitative findings from the victims' perspective, and finally, the input from GPs. The last section in this discusses employing the findings for health promotion and the role of support groups and participants to improve it.

Chapter 5: The fifth chapter discusses the results presented in chapter 5, integrating them for triangulation and to explain each other.

Chapter 6: This chapter provides an overall conclusion of this study to guide future research, in additions to the researcher's reflections on this research journey.

Chapter 2

Literature review

2.1 Introduction

‘Illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted’ (Bury, 1982, p. 169)

It has been more than three decades since Bury (1982) proposed conceptualising chronic illness as a disruptive event in a person’s life; the diagnosis of a chronic disease is a shock and the individual’s life may never be the same afterwards. As years passed, narratives sharing the same pattern of disruption of everyday life and health emerged, such as ‘My whole life stopped’, or ‘My health has not been the same since’ (Short et al., 2014, p. 4). However, this time the disruptive event was cyber-victimisation.

This literature review provides a supportive background to this study in the form of an argument to locate this research within the existing literature, highlights gaps in terms of knowledge, study population and approaches adopted. It consists of three main sections: a) supportive background, discussed in sections 2.2 and 2.3 and published in a book chapter (section 2.2.4), b) a systematic review to examine the documented scope and impact of cyber-victimisation on people with chronic conditions, published in a peer reviewed journal (section 2.4), and c) the development of the conceptual framework underpinning this study (section 3.5).

2.2 Chronic conditions

This part of the literature review chapter provides a background on the self-management of chronic conditions, managing health conditions online, and targeting people with disabilities.

2.2.1 Chronic diseases in medicine and public health

The term “chronic” is derived from the Greek word “khronos” which means “time” (Oxford, 2015). This indicates the most important feature of a chronic condition, which is described in Oxford dictionaries as an illness persisting for a long time or with a recurring nature (Oxford, 2015). In medicine, “chronic” is a general term referring to a group of diseases characterised by long duration, frequent recurrence and slow progression (Merriam-Webster, 2015). The medical definition of chronicity includes conditions resulting from infectious agents such as tuberculosis or HIV/AID. From the lens of international health organisations, such as the WHO and the Centers for Disease Control (CDC), chronic diseases mostly refer to non-communicable diseases (NCD), which are characterised by long duration and slow progression. These are mainly cardiovascular diseases, diabetes, cancers, chronic respiratory diseases including asthma and chronic obstructive pulmonary disease (World Health Organization, 2014; Centers for Disease Control and Prevention, 2018). In the field of public health, the attention in research is towards chronic non-communicable diseases (NCD), because they represent the leading causes of morbidity and mortality worldwide, including the UK (World Health Organization, 2014).

The duration of a chronic condition varies depending on the definition. In pathology, when a physiological disturbance lasts more than two to four weeks, the condition is described as chronic, such as chronic diarrhoea (Centers for Disease Control and Prevention, 2011). However, in the case of clinical diagnosis of chronic disease the minimum duration of symptoms is three to six months, for example in the case of diabetes Glycated Haemoglobin

(HbA1C) indicates the level of glucose in plasma for the past one to three months and it is one of the diagnostic criteria (American Diabetes Association, 2015; World Health Organization, 2014). Hence, in general patients with chronic conditions are advised to attend follow up appointments every three months (BMJ Best Practice, 2015a). Based on these definitions, duration and follow up requirements, in addition to keeping in mind that chronic conditions are mostly not curable (World Health Organization, 2015). Hence, these conditions have an impact on individual's life and require full commitment to managing the condition. This commitment is to be taken by the individual to take medications, adopt a certain lifestyle, and make everyday life decisions in order to reach the best possible quality of life (Greenhalgh, 2009). Such commitment is highly related to the concept of self-management which will be further discussed in the next section.

2.2.2 The self-management of chronic conditions

Self-management implies the involvement of patients in their own care (Greenhalgh, 2009). For many professionals, it represents the foundation of care, contributes to better disease control, and minimises the cost of interventions and complications (Greenhalgh, 2009). Patients consider self-management as bringing order to their lives to cope with their conditions (Kralik et al., 2004). It aims at patient involvement in treatment and its effect on life. However, the self-management of each condition has a different goal, for example, in asthma the main target is to adhere to treatment and prevent exacerbation, in diabetes it is about blood glucose control and lifestyle, while in arthritis the focus is managing pain and disability (Newman, Steed and Mulligan, 2004). Accordingly, self-management is demanding physically, emotionally, intellectually and socially (Hinder and Greenhalgh, 2012).

In an analysis of coping with chronic conditions, Greenhalgh (2009) argues that four different perspectives of involving the patients and the public in managing chronic conditions are documented. Firstly, in medicine a self-management approach is generally adopted

drawing on cognitive psychology. It implies that a self-management plan requires two types of resources: psychological such as self-efficacy, and skills such as self-monitoring or injecting. The assumed change in the medical approach will be gaining knowledge, skills and motivation, and success in such approach is defined by adherence to this plan, improvement in disease markers and psychological wellbeing. This approach is sometimes considered to be the best model, and evidence showed that it is the most effective intervention in chronic diseases (Norris, Engelgau and Narayan, 2001).

Secondly, in medical sociology, the concept of self-management draws on narrative theory (Greenhalgh, 2009). It is about coping with the illness and going on with life by getting support from people who are going through the same experience. An example of this is peer support, which was found to be effective internationally in diabetes management, however it is not yet fully implemented in health systems (Heisler, 2010; Fisher et al., 2010). Greenhalgh (2009) argued that this approach is separate from self-management. Nevertheless, it could be seen from another point of view as complementary to self-management, because coping skills and support gained from peers may eventually be perceived as a psychological resource in the medical approach of self-management. This is supported by a clinical trial carried by Lorig et al. (2000) in the United States, which highlighted the importance of bringing patients with chronic conditions together as a form of self-management. Lorig et al. (2000) included different chronic conditions, which may indicate how self-management is not only pathology-related but relies also on self-efficacy. Thirdly, the whole system approach in involving people in care, which draws on social ecology (Greenhalgh, 2009). Fourthly, critical public health approach which draws on critical sociology (Greenhalgh, 2009). However, the last two approaches consider the whole social structure to support the individual which is not the focus of this work but could be used in future studies.

For chronic conditions, self-management is being advocated as the best approach to manage long-term health conditions, however, reaching optimum health outcomes is not

always achievable (Newman, Steed and Mulligan, 2004). This is due to adherence issues and psychological impact. Hence, there are many influences on the management of chronic conditions, for example material conditions such as the availability of food or water, national and local regulations (Glass and McAtee, 2006). Other factors are related to socioeconomic status, cultural norms which influence lifestyles such as smoking or drinking, and work environment (Glass and McAtee, 2006). These factors directly or indirectly influence the self-management of chronic conditions, which fit within a model described by the Centre for Managing Chronic Disease in the United States. The model takes the form of a "circle of influence", the circle locates self-management by the individual as the core of care, it is then encircled by bigger influencers in the following order: family, clinical professionals, work, community awareness, environment and policies (Center for Managing Chronic Disease, 2015).

Accordingly, self-management is theoretically the best possible intervention to manage chronic conditions, but its practical implementation can be disturbed. This disturbance comes from the argument that self-management relies on psychological resources (Greenhalgh, 2009). The documented link between stress and victimisation (Dreßing et al., 2014) makes cyber-victimisation a potential influence that directly depletes psychological resources, and hence the core of self-management. This notion is supported by the findings of a systematic review examining self-management interventions in individuals aged 7 to 25 years (Sattoe et al., 2015). This review included 86 studies, included from six databases, it highlighted the formats, theories and outcomes of self-management, and concluded that most studies focused on the medical aspect of self-management while the psycho-social aspect was ignored (Sattoe et al., 2015). Hence, there is an increasing need to address the link between cyber-victimisation and self-management of health. The link and influencing factors will be further discussed under the theoretical framework (section 2.5).

2.2.3 Managing chronic conditions online

With the advancements in electronic communication, the online self-management of chronic conditions was investigated. A clinical trial was conducted in the United States to test web-based chronic diseases self-management (Lorig et al., 2006) of 958 patients with cardiovascular diseases, respiratory diseases and diabetes. The outcome was evaluated based on health status, health behaviour, as well as emergency and doctor visits. This trial showed that these web-based interventions were comparable to 'offline' self-management of chronic diseases (Lorig et al., 2006). However, a literature review of the self-management of chronic diseases using social media (Merolli, Gray and Martin-Sanchez, 2013), the search in four databases eventually included 19 studies and found improvements in psychosocial aspects of management compared to physical improvements. It was concluded that further research is needed to evaluate the potential use of social networks (Merolli, Gray and Martin-Sanchez, 2013). It is of note that the study population in the included studies was young, and that the included studies advocated the use of technology in health interventions with a tendency to report positive findings. Hence, Merolli, Gray and Martin-Sanchez (2013) considered the lack of reporting negative findings a limitation to their review.

Positive findings and the potential use of the Internet for communication are still encouraged, for example, in a recent review on the effectiveness of online delivered diabetes interventions, only positive findings were reported (Pereira et al., 2015). Another concern about using the Internet as a medium for self-management from a systematic review, which included 85 articles regarding online self-management of asthma, is that the majority of online content is not evidence based (Al-Durra and Torio, 2015). It may be inappropriate to compare findings because of the differences in the chronic condition in focus or the age group included, but these differences highlight that the era of self-management and the use of technology in this intervention is still developing. Hence, studying the potential negative aspects of this is vital. This is of particular importance to cyber-victimisation research because neglecting

potential harm in the use of such technology with people with chronic conditions might have adverse effects, which implies the need for further research.

2.2.4 Chronic conditions, disability and victimisation

In the literature, there is a significant association between having a chronic condition and being a victim of harassment among the young age group (Sentenac et al., 2011a). Pre-existing chronic condition can result in disability, and vice versa (Krahn, Reyes and Fox, 2014). For example, 25% of people with chronic conditions have disabilities, and 80-90% of people with disabilities have chronic conditions (Gulley, Rasch and Chan, 2011).

The internet has provided people with disabilities with the sense of identity and belonging (Seale and Chadwick, 2017). Peer support provides an important factor to improve the psychosocial aspect of the self-management of chronic conditions, however, peers can be a source of stress themselves. This can be seen in studies examining the victimisation of individuals with chronic conditions by their peers. For example, in a survey conducted in Canada researchers found that children with epilepsy were victimised and bullied in school compared to “healthy” children or young people living with chronic kidney disease (Hamiwka et al., 2009). Indeed, these findings are consistent with other studies as will be further discussed. Victimising young individuals is usually termed bullying, it resembles stalking and harassment in many aspects, the term is common among young victims especially school age. It involves verbal or physical hostile actions that are repeated, cause distress and with power differences between the offender and the victim (Sentenac et al., 2011b). The differences between the types of victimisations are covered in the systematic review (section 2.4) (Appendix 7), and in section 2.3.

In another study of 12,048 students aged 11, 13, 14 years bullying victimisation was compared between Ireland and France (Sentenac et al., 2011b). It was found that children

living with chronic conditions such as diabetes, arthritis, cerebral palsy and allergies were frequently victimised by their peers. The prevalence of victimisation was 20.6% in Ireland and 16.6% in France (Sentenac et al., 2011b). This is also supported by findings from a systematic review of 59 studies exploring the risk of victimising children having chronic conditions (Sentenac et al., 2011a). The researchers covered a wide range of conditions including diabetes, asthma, psychiatric conditions, learning difficulties, and physical impairments. The participants experienced victimisation, and this has disrupted their self-management by affecting their adherence to treatment, in addition to reporting depression symptoms (Sentenac et al., 2011a). Additionally, people with diabetes were victimised because of their lifestyle related-management, such as diet and using insulin injections. While asthma patients perceived that they were stigmatised for using medications, and in both cases, self-management was disrupted (Sentenac et al., 2011a).

It is to be noted that conditions with physical signs such as eczema- which is a dermatological condition- have a higher risk of victimisation compared to relatively invisible conditions like asthma or seasonal allergies (Sentenac et al., 2011a). This may show differences in the cases of pure cyber-victimisation. However, it may explain why overweight children are victimised, because in this review overweight children were targeted (Sentenac et al., 2011a). This goes in line with qualitative findings from a study in Canada which reported harassment targeting girls because of their weight (Mishna, McLuckie and Saini, 2009).

It is acknowledged that in the area of internet use and disabilities further research is needed (Kowalski et al., 2014; Alhaboby et al., 2017b). Such research would benefit from methodologies employed with people with disabilities that allow more input from participants' perspectives such as using participatory approach (Nind and Vinha, 2014), and employing qualitative methods (Nind, 2009; Short et al., 2014). These approaches are scarce in the area of cyber-victimisation of people with long-term conditions (Alhaboby et al., 2017b). One of the few qualitative studies was carried out in Canada (Mishna, McLuckie and Saini, 2009), the

researchers examined youth perspectives in an anonymous sample of individuals aged 11 and 24 years. The sample included participants' calls to a free national bilingual phone and web counselling referral service and examined youth perspectives on online relationships. Generally, the participants felt safe and trusted given information online. The impact of cyber-victimisation included depression, confusion, guilt and shame, self-harm and social withdrawal. Strategies to cope with this were mostly denial of seriousness and avoidance of persons involved (Mishna, McLuckie and Saini, 2009). Cyberstalking was identified as a subtype of cyberbullying in this research (Mishna, McLuckie and Saini, 2009). The youngest victim of cyberstalking in this research was 11 years old girl (Mishna, McLuckie and Saini, 2009). This is not unusual because according to the Office for National Statistics, almost 80% of people aged 16-24 years in the UK access the Internet daily, 91% of them use it for social activities (Office for National Statistics, 2014), which increases the risk of being victimised. The harassment took the form of excessive emails, from known people or strangers and ranging from unwanted annoying content to death threats. Ignoring such communication or blocking the person did not help in stopping the contact. This resulted in a terrifying experience and controversial disclosure to family and support seeking (Mishna, McLuckie and Saini, 2009).

One of the lessons learned from the studies above is that people with chronic conditions were targeted and this was studied extensively in childhood. However, there is a gap in studying this in older age groups and this raises questions related to victimising people with long-term conditions and the role of technology.

2.2.4.1 Targeting people with disabilities

Discrimination against people with disabilities goes back to ancient history when disabled people were used as 'scapegoats' through cultural justifications (Quarmby, 2011). Over the years, the construction of disability has been influenced by changes in cultures,

communities and communication. The involvement of the Internet as a new means of communication has created a new context that further reshaped this risk (Wells and Mitchell, 2014). It is estimated that 62.5% of adults with disabilities in the United States have high-speed Internet access (File and Ryan, 2014). Further, one in every five people living with long-term conditions participate in online health discussions (Fox and Purcell, 2010). In the UK, 75% of people with disabilities have online access, 97.3% of adults aged 16 to 24 years with disabilities were recent Internet users in 2016 (Office for National Statistics, 2016). Internet use by people with a physical disability was not significantly different from people without physical disabilities, but the difference was significant in the case of intellectual disabilities (Wells and Mitchell, 2014). These figures might not be fully accurate considering the differences between specific types of disabilities, but they do reflect the instrumental role the Internet plays in everyday life. Hence, recognizing its potential and risks is required.

The quest for disability rights has undergone numerous improvements in recent years. The public has raised their consciousness regarding terminology use for example. People are encouraged to utilize inclusive language instead of passive or stereotypical terminology such as ‘crippled’, ‘handicapped’ or ‘mentally retarded’(Office for Disability Issues, 2014c). Despite improvements in recognizing disability rights, people with disabilities still endure discrimination from online offenders who use offensive language (Pring, 2016). To understand how the Internet is used to perpetuate this prejudice, it is necessary to understand the context under which the models of disability discourse operate.

The way in which disability is conceptualised by individuals and organisations impacts people’s understanding and subsequently influences their language, expectations, and interactions in society (Haegele and Hodge, 2016). The medical and social models of disability are the two prominent models that frame disability. From the medical perspective, disability is seen as a ‘deficit’, an impairment in body functions as a result of disease or injury that requires normalization through diagnosis and treatment (Humpage, 2007; Forhan, 2009). Hence, in

this model, disability is perceived as a negative individual trait that overlooks the value and needs of people with disabilities (Haegele and Hodge, 2016). The social model views disability as a construct that is imposed on the impairment. Thus, disability in of itself is neither a positive nor a negative attribute. Rather, it is the society's responsibility to be more inclusive towards people with disabilities (Anastasiou and Kauffman, 2013). Nevertheless, by shifting responsibility for change toward society, the social model might lead one to overlook an individual's impairment as a part of their lived experience (Haegele and Hodge, 2016). Anastasiou and Kauffman (2013) argue that disability is different from other human diversity components, such as ethnicity, due to the underlying biomedical element. The impairment forms a part of everyday life that influences people's choices. Thus, people with disabilities will benefit from addressing both the biomedical and social dimensions. However, the unclear demarcation in adopting the medical and the social models has potentially created confusion and societal stereotyping of disability which subsequently led to victimisation.

Vulnerability was a term used mostly in research to describe an individual or a group of people who require protection (Levine et al., 2004). To avoid blaming the individuals for being abused, the term "vulnerable adult" was replaced by "adult at risk" by the Office of the Public Guardian (Office of the Public Guardian, 2017). The discourse related to people with disabilities and being at risk of discrimination is multifaceted. One aspect of this complicated discourse is how disability is stereotypically linked with illness. For instance, in the UK, disability is constructed legally as a long-term physical or mental impairment (Equality Act 2010), and hence the legal definition is similar to the medical perspective. Another facet is what happens when one acquires a disability status. Once the sick role is legitimized medically, disability is then perceived as a title associated with reward. A good example of this is when one fulfils the legal definition of disability and hence acquires disability benefits in the UK. These individuals are then perceived as consumers and subsequently face offensive language by taxpayers such as being called 'scroungers', 'workshy' or 'cheats' (Briant, Watson

and Philo, 2013). Emerson and Roulstone (2014) argue that this approach in identifying disabilities and the subsequent compensations has led to a systematic error in institutions by consistently attaching negative value judgments to disability, which facilitate further stereotyping by the public in linking disability with either severe illness or fraud. These two aspects, linking disability with visible illness and referring to disability as beneficiary status, have contributed to discrimination against disabled people. For instance, the public may assume that only people with visible physical disabilities who use wheelchairs can use accessible parking areas. Should anyone else utilise these spaces, they are then perceived as committing fraud by the public. In turn, some disabled people were frequently reported to the police when using accessible parking areas and were called “scroungers” and “bogus claimants” (Quarmby, 2015). Taking the UK as an example, due to cost and tax issues, the typical newspaper story about disability is increasingly focused on fraud cases to get disability benefits (Briant, Watson and Philo, 2013). These assumptions have reinforced the public’s willingness to stereotype, and influenced the experiences of discrimination of disabled people in their communities.

A recent UK survey explored the perceived motivation of offenders in disability hate crimes. It found that 89% of respondents identified themselves as disabled, and 87.2% experienced a minimum of one harassment offense (Quarmby, 2015). The motivation of offenders ranged between hate, jealousy and accusations of fraud because of the relative invisibility of some disabilities. Hence, one of the major aspects surrounding disability discrimination is the immediate socio-cultural context and perceived level of disability. Moreover, being different from the majority of the population, physically (Horowitz et al., 2004), intellectually (Kowalski and Fedina, 2011) or in terms of lifestyle (Sentenac et al., 2011a), has consistently contributed to victimizing disabled people. Therefore, vulnerability in this sense is a complex situation enabled by the socio-cultural context, maximising differences and labelling, all of which ultimately lead to victimisation over the years.

2.2.4.2. Underlying factors for targeting

In addition to the ongoing vulnerability issues discussed earlier, several factors could increase the risk of victimisation of people with disabilities in online media. One of these factors is the underestimation of the seriousness of communications taking place online. There is a relatively common assumption that the Internet is 'not real' and any unwanted communication could be fixed by shutting down electronic devices or not going online (Short et al., 2014). Such assumptions are not only shared by the public, but also by some of the personnel working at supportive channels such as the police, service providers and healthcare practitioners (al-Khateeb et al., 2017). Hence, the disavowal of these service providers could influence the quality of support a victim may receive, including health support. Due to training and underestimation issues, some victims ended up changing their mobile phone numbers, jobs, homes and even country (al-Khateeb et al., 2017). Accordingly, disability in most cases is perceived as a medical issue by supportive channels, but the resultant victimization is seen as a social issue that leaves victims struggling for support (Alhaboby et al., 2016). Moreover, when people underestimate the impact of online communication, harassing others becomes easier. People who might not commit harassment offences offline could be turned into online offenders (Sheridan and Grant, 2007).

The second factor that increases one's level of victimisation is related to Internet access and utilisation by disabled people. There are anticipated differences in Internet use between people with and without disabilities. One of the differences relates to the general use of the Internet, comparing the frequency and purposes of web surfing (Lathouwers, de Moor and Didden, 2009). For example, it was presumed that people with disabilities spend longer time online due to mobility needs and utilizing online shopping services (Sheridan and Grant, 2007). However, despite these assumptions, recent studies did not find significant time differences in Internet use by disabled people (Shpigelman and Gill, 2014). Other researchers found no differences in online behaviour between people with and without disabilities except

in forming close online relationships (Wells and Mitchell, 2014). Thus, using the Internet as a means for socialization is another potential underlying factor for victimization.

Forming social relations online was further addressed specifically with individuals having intellectual disabilities because trying to socialise online put them at higher risk of victimisation (Sofronoff, Dark and Stone, 2011). The Theory of Mind was used to explain this issue (Sofronoff, Dark and Stone, 2011). Researchers in this case attempted to explain victimisation experiences by a deficit in communication skills. This resulted in framing the issue socially and, in some cases, misunderstandings in communication while building online relationships resulted in being labelled as bullies and victims at the same time (Yen et al., 2014).

The third factor is the stereotyping that happens by collectively using the term ‘disability’ when referring to a heterogeneous group of conditions. Researchers in various disciplines such as psychology, criminology and public health have undermined disability in cyber-victimization studies by constructing it as a generic term without further analysis. In some instances, ‘disability’ was used to cover all students from schools with special needs (Didden et al., 2009). Thus, reporting commonly included victims with a “physical disability”, “intellectual disability” or special need. Few studies looked specifically at ADHD, Asperger’s syndrome or autism (Yen et al., 2014). Accordingly, research of cyber abuse cases involving people with disabilities tends to overlook a wide range of conditions that exist under the disability umbrella, such as people with invisible disabilities like chronic fatigue syndrome. This contributes to how these individuals are falsely perceived by the general public, resulting in a vicious cycle of stereotyping through research, government statistics and media representation.

2.2.4.3 The way forward: confronting discrimination

The Internet, as a medium of communication, presents risks to people with disabilities but also has the potential of generating rewards. Online communities provide potentially huge benefits to people with disabilities. One such benefit is that online communication offers victims of discrimination the opportunity to confront their abusers or raise awareness of such offences. Thus, viewing the Internet as a means of empowering those who have been traditionally disempowered makes it possible to fight cyber-victimization in the long-term. Not only does this allow the victim to confront the victimizer but also generates virtual communities of people who band together to share their experiences and expand their empowerment through group membership. The Internet has provided people living with relatively overlooked disabilities such as Myalgic Encephalomyelitis (ME) with opportunities to express themselves and support each other. The perspectives of these individuals are being recognized through online campaigns which generate awareness and social change regarding the impact of ME as an invisible disability for instance. They also advocate for the re-categorization of Myalgic Encephalomyelitis as a neurological condition instead of the current psychological classification. The recognition of these efforts can contribute to reshaping how the public perceive disability beyond physical impairments, which could potentially minimize harassing this group for 'not looking ill.' Hence, it could be assumed that the online social identity developed by people with disabilities and subsequent in-group empowerment is a powerful way to counteract cyber-victimization. This could be explained by the Social Identity Theory, which involves a process of categorization, resulting into considering self as part of an in-group 'us' that is different the out-group 'them', with a tendency of bias towards the in-group (Tajfel, 2010; Turner, Brown and Tajfel, 1979). Therefore, online disability identity can be based on disabled people experiences rather than medical or research terms when people with disabilities were empowered to construct them for themselves.

One such constructed disability identity is known as the ‘spoonie’ identity, and is commonly adopted by disabled people and shared in online narratives. It is built on the Spoon Theory, which was based on a real experience shared by an online blogger (Miserandino, 2003). The blogger uses spoons to illustrate how she manages her daily life with lupus. This theory was soon adopted by thousands of people with various types of disabilities and chronic conditions who started calling themselves spoonies. The Spoon Theory acknowledges the impact that chronic illness can impose on the daily lives of people. Hence, it does not dismiss the medical aspect (Miserandino, 2003).

People with disabilities have also found creative ways to use the Internet to communicate the hardships they have endured through interacting with the public offline. The media has covered a few stories of disabled people being harassed because they are physically different, or due to being labelled ‘disabled’ but not using a wheelchair. For instance, one story relays the experience of a 27 year old Ph.D. researcher in the UK who has had Ehlers-Danlos Syndrome since birth (Cockroft, 2016). The condition is a connective tissue disorder that affects her ‘routine’ activities in which her joints could dislocate up to 40 times per day while combing hair, coughing or walking. She uses crutches and a wheelchair, but upon going out she receives harassing comments from strangers and claims that she is using the crutches to avoid work. Thus, to avoid ostracization and harassment, she often skips using the walking aids. Once while out in public, she used her disability badge to park in an accessible spot reserved for people with disabilities. Upon returning to her vehicle, she was harassed for ‘not looking disabled’ with a note that read, “Rot in hell,” and “You should be disgusted in yourself. One day I hope you know what it is like to be disabled, then you will know.” She responded to the incident by posting a picture of the note online and asking people not judge others by appearance. She wrote, “Trying so hard to not appear disabled due to hurtful comments and try to live a normal life is hard, I was really hurt by it” (Cockroft, 2016).

Despite the impact, this experience had on her, the courage in sharing it on the Internet helped to spread its impact and increases awareness on her rare condition to decrease stereotyping.

When experiences of ableism are shared through a personalised narrative, such as in the previous example, promising improvements in generating social justice, awareness and community building can be anticipated. Another example of such social change comes from a video posted on YouTube of a teen with Asperger's Syndrome. The video went viral and was covered by a number of media articles (Stout, 2015). The 14-year old boy from Hertfordshire used a selfie stick to attach his mother's video camera and record videos that explain, in his own words, how cyberbullying messages impact him. The selfie stick usually comes with an extendible handle and fits smartphones or cameras to capture a photo or a picture of oneself. It is for anyone's use but could have special importance when used by people with disabilities because it accommodates limited mobility (Berry, 2016). Additionally, the creative use of a selfie-stick to self-record and share the impact of cyberbullying via the Internet helped in touching the lived-experience of usually isolated victims. The boy's short video was a poignant illustration for how individuals with disabilities experience cyber-victimization. As a result, it was shared by thousands of people who felt moral indignation about the incidents. Such initiatives indicate the potential of using the Internet to communicate, fight cyber-victimization and influence public opinion. However, it should be noted that using the Internet media itself to counteract cyber-victimization has its own risks. For instance, the comments and responses by others could also generate further negative comments and harassment. Despite this potential, the longer term benefits of having an open dialogue about these issues could be a key factor to improve public awareness and prevent future cyber-victimisation.

2.3 Victimisation and cyber-victimisation

This section discusses offline victimisation as a precursor to cyber-victimisation, the emergence of cyber-victimisation, the impact upon victims and support available.

2.3.1. Offline victimisation

Victimisation can be described as any unwanted attention or negative behaviour over time, it can be by an individual or a group, against the victim, and sometimes more than one victim could be involved (Kouwenberg et al., 2012). The victimisation of disabled people is widely documented; it is an international issue that is not linked to a specific condition yet. In Canada, individuals with epilepsy were victimised in schools (Hamiwka et al., 2009). In Ireland and France, young individuals with chronic conditions, such as diabetes, arthritis, and cerebral palsy, were frequently targeted by their peers (Sentenac et al., 2011b). Individuals with intellectual disabilities, such as ADHD and autism, were victimised in the United States (Taylor et al., 2010; Chen and Schwartz, 2012), while young people with hearing impairments were discriminated against in the Netherlands (Kouwenberg et al., 2012). Nonetheless, despite the geographical variations and figures, the impact of victimisation is consistent.

2.3.2 Online context and cyber-victimisation

With the dramatic increase of Internet use, electronic means such as email, phone messages, blogs or social networking websites/apps (including Facebook, Twitter, Instagram, YouTube and others) have become part of everyday life. For example, more than 80% of the population in the UK has Internet access, including the least deprived areas (Office for National Statistics, 2015). Internet use has numerous benefits in facilitating networking for social purposes or to get health information or support (Algtewi, Owens and Baker, 2015). Indeed, this virtual context became available for both people with disabilities and offenders.

However, despite the benefits, the Internet is associated with the risk of online discrimination experiences, or what is generally known as ‘cyber-victimisation’.

2.3.2.1 Cyber-victimisation terminology

Cyber-victimisation is an umbrella term covering a range of cyber offences such as cyber-harassment, cyberbullying, cyberstalking, cyber-disability hate crimes or cyber sexual exploitation. Each of these terms has its own definition that could vary between disciplines, however, they share the criteria of being an antisocial behaviour by the ‘offender’ towards the ‘victim’ via electronic communication causing fear and distress . This is achieved by sending harassing content, insults, creating false profiles, spreading lies or contacting the social network of the victim.

Cyber-harassment is regarded as negative attitudes or intimidating behaviours towards the victim involving the use of the Internet and/or cell phone. An example of a study that looked at cyber-victimisation of disabled people and used the term cyber-harassment is the work by Fridh, Lindström and Rosvall (2015). This cross-sectional public health study in Sweden sampled 8,544 people, of which, 762 individuals had disabilities. Participants were aged 12, 15 and 17 years with self-reported impaired hearing, impaired vision, reading/writing disorders, dyslexia, and ADHD. Cyber-harassment in this study was defined as a violation or harassment over the past 12 months, involving cell phones or the Internet such as email, Facebook, and text messages. Male participants reported a frequency of cyberharassmnt of 32.1% (one incident) to 41.5% (several incidents), while female participants reported 28% and 35% frequencies respectively. The impact upon victims was mainly subjective health complaints.

When the intimidation in harassment is associated with power imbalances, this perceived unequal power relation between the victim and the offender is described as

cyberbullying. Such experiences are common in schools and the workplace due to the nature of relationships between the involved parties. A public health study in Sweden (Annerbäck, Sahlqvist and Wingren, 2014) looked at 413 participants aged 13–15 years, drawn from a sample of 5,248 participants. The participants had a variety of conditions including impaired hearing or vision, limited motor function, dyslexia, ADHD, asthma, diabetes, epilepsy and intestinal diseases. Cyberbullying was defined as an indirect form of bullying, indicating harassment via the Internet or mobile phones in the past two months and involving the use of power to control others or cause distress. The impact reported was poor health, mental health consequences and self-harm (Annerbäck, Sahlqvist and Wingren, 2014).

Another cyber-offence is *cyberstalking*, which also involves repeated unwanted contact triggering fear and distress, however, it is also characterised by fixation. Hence, scholars identify cyberstalking cases by the repetition of ten harassment incidents over a period of four weeks (Sheridan and Grant, 2007). Cyberstalking can be regarded as a phenomenon by itself or an evolution to stalking by giving offenders new relatively easy methods to target the victim (Bocij and McFarlane, 2003). There is a growing body of literature covering stalking as an ancient crime and with the surge of using technology in everyday life, cyberstalking literature has increased (Bocij and McFarlane, 2003). Two types of studies emerged on review of the literature, studies that discuss stalking, introducing electronic means as new methods of stalking, referred to as cases of combined stalking and cyberstalking (Davis, Coker and Sanderson, 2002) and more recently, cyberstalking addressed in studies purely focusing on this phenomenon (Dreßing et al., 2014). In both cases, authors tended to introduce the topic by discussing offline offences first. In a study of cyberstalking victims, the main target population was not people with chronic conditions (Sheridan and Grant, 2007), however, 11.9% of pure cyberstalking cases were against people with disabilities. More than ten years ago in criminology, cyberstalking was defined as harassing or threatening a person or a group more than once using the Internet or electronic communication (Bocij and McFarlane, 2003).

Hence, it shares the same building blocks of offline victimisation definition and adding to it, electronic communication. While harassment was considered as a type of cyberstalking in crimes (Bocij, Bocij and McFarlane, 2003; Bocij and McFarlane, 2003), it was separated as cyber-harassment in another study and defined as planned intimidation using electronic means (Maple, Short and Brown, 2011).

2.3.2.2 Inconsistency in defining cyber-victimisation

The definitions above are not consistent in the literature, they overlap and vary between disciplines and individual studies. For example, online harassment or cyber-harassment, may also be referred to as trolling, and it is also related to cyberstalking. Both cyberstalking and cyber-harassment involve receiving online offending comments, spreading lies, insults or threats, frequently causing a significant negative impact on 'victims' (Short et al., 2014). Additionally, in UK legislation, the Crown Prosecution Service (CPS) identifies cyberstalking as a type of harassment taking place online (Crown Prosecution Service, 2018b) and they are covered under the same legislation depending on the details related to each specific case, as will be discussed below.

There are numerous issues surrounding the definitions above. Firstly, when looking at online experiences, it is difficult to identify a threshold for the number of incidents, for instance, whether each email or Facebook comment is an incident, or whether each platform e.g., Facebook or Twitter is an incident. Secondly, the duration to identify a victimisation experience also varies, some researchers use a lifetime approach (Mueller-Johnson, Eisner and Obsuth, 2014), others look at weekly, monthly or yearly experiences (Didden et al., 2009). Thirdly, when cyber-victimisation is perceived to be a result of hostility or prejudice, any of these offences could also be labelled as a cyber-disability hate crime, which has only been recognised recently (Alhaboby et al., 2016). Fourthly, people who experience cyber-victimisation do not necessarily identify themselves as victims.

Regarding cyberstalking, researchers (Dreßing et al., 2014) argue that variations in the definition of cyberstalking is reflected through the wide range of documented cyberstalking prevalence. Internationally, the prevalence of cyberstalking ranges between 3.2 to 82%, with studies in the United States reporting 3.2% (Fisher, Cullen and Turner, 2002), 3.7% (Alexy et al., 2005) and up to 40.8% (Reyns, Henson and Fisher, 2012). Moreover, stalking definitions show differences between specialties, as well as between practitioners and researchers (Sheridan, Blaauw and Davies, 2003); these differences are related to details in the description rather than the big picture.

Comparing offline and cyber-victimisation, in clinical psychology literature, offline stalking is described as abnormal behaviour and characterised by persistence, that is, abnormal, persistent, and unwanted attention (Kamphuis et al., 2005). While it is a challenge to define what is abnormal, the two other criteria, persistent and unwanted, are consistent with definitions in other specialties in the literature. In forensic psychiatry definitions, stalking is considered as a pattern of behaviour characterised by fixated threats and intrusions, triggering fear and anxiety (McEwan et al., 2012). In law, stalking is regarded as a type of violence differing from other types in duration, which can be months or up to years, and the fear it causes, especially when this distressing conduct is seen as harmless by others (Kropp et al., 2011). In Canada, there was an attempt to develop guidelines to assess the risk to being victimised, the nature of stalking and preparatory risk factor, stalking was defined as an unwanted repeated contact or conduct that deliberately or recklessly affects people resulting in experiencing fear or safety concerns of self or others (Kropp et al., 2011). Probably because violence is closely related to criminology literature, the definition adopted in criminology and clinical practice shares some similarities to the approach in law (Davis, Coker and Sanderson, 2002). In the United States, a national survey to study the effects of stalking defined a stalking case as having one or more incidents associated with any degree of fear (Davis, Coker and Sanderson, 2002). Hence, fear and distress resulting from victimisation may have a bigger

impact on health than physical violence, which is an important issue in the case of cyber-victimisation as will be discussed in the next section.

Despite these differences, Sheridan, Blaauw and Davies (2003) described stalking as 'chronic, consisting of a number of nuisance behaviours that appear consistent over countries and samples' (Sheridan, Blaauw and Davies, 2003, P. 148). Consequently, the main building blocks of defining stalking are the repeated nature, unwanted contact, and triggering distress of fear. Nonetheless, it should be noted that not all the previously mentioned definitions included distress, possibly because distress is related to victims' awareness of being stalked, or because it is generally an impact rather than a part of the stalking behaviour. The consideration of fear and distress in the definition narrows the affected group and it scientifically explains the impact on health (Pinel, 2011). Hence, to further address the impact of cyber-victimisation, the role of distress and fear was considered (section 3.3.2). In the UK, the University of Leicester conducted a national stalking survey in 2005 supported by the Network for Surviving Stalking (Sheridan, 2005). Out of the 1,300 subjects, 1,051 participants aged 10–71 years were included, while the others were excluded due to an incompletion or when the case was seen to be delusional or not serious. It was found that 60% of participants experienced stalking in the UK by various methods, 86% of them were females, 58% were very frightened and the stalkers obtained information about the victim from people around and the Internet. While the study focus was stalking, using the Internet by the stalker represents the transition area between stalking and cyberstalking. Based on all these issues in defining the offence, its duration and number of incidents, the prevalence of cyber-victimisation against people with long-term conditions is not clearly determined; it may range between 2% (Didden et al., 2009) to 41.5% (Fridh, Lindström and Rosvall, 2015).

Despite variations, it could be assumed that all of these cyber-victimisation experiences are potentially more devastating than their counter-traditional ones (Anderson, Bresnahan and Musatics, 2014). In fact, cyber-victimisation is further complicated by international cross-

border offences where the offenders are overseas and the police face difficulties in following up such cases (Sheridan and Grant, 2007). Further definitions of cyber-victimisation are provided in section 2.3.2.1, and Appendix 7.

Differences in definitions could be one of the reasons behind this variation, but other factors could have contributed to this, such as using online surveys (Dreßing et al., 2014), which cannot be generalised to the whole population (Boynton and Greenhalgh, 2004). It must be acknowledged that the advantages of an online survey made it the method of choice to contact a relatively unreachable population due to their physical and social constraints, probably resulting from the impact of being a victim (Maple, Short and Brown, 2011). The other factor is that these studies did not have a focused population, when the focus was attempted, it was either based on gender, age group or college context (King-Ries, 2011; Reyns, Henson and Fisher, 2012). Limiting research to a young age group is questionable, since the ONS in the UK reported that surprisingly Internet use was 84% by all age groups in 2014 (Office for National Statistics, 2014). With regard to context, colleges may not reflect the whole aspect of cyber-victimisation phenomenon, furthermore, social research college students are considered an easily accessible population (Boynton and Greenhalgh, 2004). Accordingly, there were few, if any, studies considering other population groups, such as people living chronic diseases who comprise 30% of the UK population (Department of Health and Social Care, 2012) and already are living with compromised health (World Health Organization, 2015).

2.3.3 The impact of victimisation and cyber-victimisation

2.3.3.1 The impact of victimisation on health

The documented impact of victimisation includes short and long-term consequences. Psychological complications involve low self-esteem, anxiety and depression, social isolation,

suicide, and unemployment (Hugh-Jones and Smith, 1999; Sheridan and Grant, 2007). In addition, health complications include physical health complaints (Sentenac et al., 2013), exacerbation of illness (Zinner et al., 2012) and disruption of health management (Sentenac et al., 2011a). Hence, in an offline context, victimisation experiences against people with long-term conditions are devastating, and the introduction of the Internet in everyday communication has added to the complexity of the issue.

Offline victimisation of adults results in serious psychological and physical harm, with long-term distress often leading to long-term mental illness (Kropp et al., 2011). It was found to be associated with negative health consequences in both males and females, direct physical effects resulting from violence were documented but it was found that fear of violence and the unpredictable nature of intrusions have more impact on health (Davis, Coker and Sanderson, 2002). Hence, long-term impact results mainly from stress, rather than direct physical trauma, which may indicate the seriousness of cyber-victimisation long-term consequences.

Pathe and Mullen (1997) studied the impact of stalking on 100 self-classified stalking victims. The means of stalking could also be related to cyberstalking, because they included telephone calls threats and due to the variations in definition as discussed earlier. Participants reported general deterioration of health, they reported anxiety 83%, flashbacks 55%, headache 47%, gastrointestinal symptoms 23–30%, eating disorders and weight fluctuations 45–48%, excessive tiredness 55%, and smoking or excessive drinking (Pathe and Mullen, 1997). Other aspects of life were severely compromised, such as employment 53%, changing home 39%, and 55% of participants had clinical symptoms of PTSD (Pathe and Mullen, 1997). Persistent stress results in negative health consequences and PTSD (Maple, Short and Brown, 2011). PTSD is a condition that develops immediately or delayed after experiencing an extremely stressful event such as disasters. It is characterised by repetitive recalling of the stressful experience as flashbacks of the stressor or nightmares, avoiding people or situations

related to the stressor, changes in mood and cognition as well as symptoms of increased psychological activity (World Health Organization, 1992). Dapice (2006) argued that it is even more accurate to describe it as continuous traumatic stress disorder.

More recently in the UK, 92% of stalking victims complained of physical effects and 98% complained of emotional effects, including anxiety, sleep disturbances, depression, phobia, loss of appetite, PTSD, suicidal ideation and violence (Sheridan, 2005). This was also found to be applicable to cyber offences; there is an evidence that cyberstalking causes major psychosocial impact upon victims (Dreßing et al., 2014). In addition to poor mental health resulting from fear, offline victimisation results in negative methods of coping with stress such as excessive drinking, drug use or excessive use of prescribed medications (Davis, Coker and Sanderson, 2002). These coping methods have negative consequences as they are unhealthy behaviours and risk factors for developing chronic conditions.

Offline victimisation also causes financial issues, not only on a personal level, but also on national levels. In the United States, the Centre for Diseases Control (CDC) estimated that stalking has a financial cost of 342 million US dollars due to treating mental health complications (Department of Health and Human Services, 2003). This was similar to the UK as stalking resulted in financial loss due to covering therapy, legal costs and repair (Sheridan, 2005). This might also have an impact on people with chronic conditions who are already coping with impairments.

Stress leads to neurohormonal changes in the blood, increasing cortisol, catecholamines and insulin secretion resulting in increased blood glucose, heartbeat, blood pressure, urination and other changes (Pinel, 2011). Thus, the stress caused by cyber-victimisation has a potential impact on people with chronic conditions, because it interferes directly on the changes in their bodies or indirectly via behavioural changes, but this was not studied, but rather the focus was on mental illnesses. Mental health consequences were

studied in literature and showed subjective reactions to this experience, taking the form of fear, anger, depression, irritation and loss of control of one's life. It is argued that there is an underestimation in reporting mental health issues due to cultural influences (Davis, Coker and Sanderson, 2002). Additional possible role of cultural constraints is that women were found to be 13 times more likely to report fear, while men were less so (Davis, Coker and Sanderson, 2002). The relationship between gender differences was discussed earlier.

Quantitative studies have dominated cyber-victimisation literature (Alexy et al., 2005; Dreßing et al., 2014; Maple, Short and Brown, 2011). One of the few qualitative studies was an online survey of 100 self-identified cyberstalking victims aged 15–68 years which thematically analysed the participants' narratives. Five overarching themes emerged: control and intimidation, determined offender, development of harassment, negative consequences and lack of support (Short et al., 2014). Negative consequences of cyberstalking identified were psychological including PTSD, panic attacks and flashbacks, physical effects and social impact. Some participants expressed being anxious, very ill, depressed, as well as long-term health effects. One participant stated that she had a miscarriage as a result of the stress she experienced due to cyberstalking (Short et al., 2014). Cyberstalking differs from offline stalking in the type of invasion, in cyberstalking it is technical, while there is a greater risk of physical violence with offline stalking. The other difference observed was in the victim-stalker relationship, which was found to be more intimate in offline stalking, while acquaintance is the most common relationship in cyberstalking. Finally, the majority of stalking perpetrators were males, but this was unclear in the case of cyberstalking (Short et al., 2014).

As a result of this comparison, researchers (Dreßing et al., 2014) found that offline and cyber-victimisation have comparable effects. Short et al. (2014) suggested these effects are comparable when there are more social and psychological effects than direct physical effects. This is of importance to this study because of the limited literature on cyber-victimisation, the effects could be drawn from victimisation literature. Additionally, in the case of chronic

diseases, the anticipated effect is related to the harm of prolonged stress and neurohormonal changes in the body (Pinel, 2011), which are represented in social and psychological effects in the case of cyber-victimisation rather than violence.

2.3.4 Available support for people who experience cyber-victimisation

Response and support available to victims of cyber offences could be divided into informal support and instrumental support. Informal support includes approaching friends and family, while instrumental help is the formal support through channels available to victims to help in coping with the experience of cyber-victimisation (Galeazzi et al., 2009; Reyns and Englebrecht, 2014). Instrumental support includes health and psychological strategies such as mental health support, and problem-solving strategies such as employing lawyers and actions by the police.

Within the UK, there are a number of legislative acts to respond to cyber-harassment such as the Protection from Harassment Act 1997, the Malicious Communications 1988, the Communications Act 2003, the Crime and Disorder Act 1998 and the Equality Act 2010 (Crown Prosecution Service, 2018b). When the victim is labelled as disabled, the harassment could also be addressed under the Disability Discrimination Act 1995 , the Equality Act 2010 or the Communications Act 2003, section 127 for disability hate crime (Crown Prosecution Service, 2018b). Despite the availability of a number of legal remedies, victims with disabilities seem to be struggling to get support (Alhaboby et al., 2016). This could be either due to the relative ambiguity of cyber offences accompanied by the unclear thresholds in legal acts, where people working in instrumental support channels lack sufficient training as discussed earlier (Appendix 24).

Another issue with support are the cases of cyber-victimisation. In the UK, 50% of offline victims complained that family and friends did not take them seriously, 50% were told they

were going mad, 42% reported to police and 61% thought they were helpful (Sheridan, 2005). This might not be very different from the professionals' responses, the majority of cyber-victims had little support and this was accompanied by blaming the victim, especially by the police (Short et al., 2014). Hence, there is a combination of the lack of support for cyberstalking victims and the risk of cyberstalking among people with disabilities (Sheridan and Grant, 2007). Accordingly, people who experience victimisation are being disempowered with a potentially significant impact on them. Hence, in order to provide proper remedies to people with long-term conditions, further training of supportive channels and increased public awareness are required.

2.3.4.1 Role of GPs and the police in supporting victims

GPs and the police build on their roles as helping professions in offline victimisation cases. A European-based study examined the recognition of victimisation in a sample of 50 GPs and 50 police officers (Fazio and Galeazzi, 2004). In Italy, GPs gave higher recognition of abnormality than police officers, probably due to their awareness with psychopathologies. The researchers concluded that recognition and response are influenced by profession and personal differences. They recommended increasing awareness via targeted information, training and multidisciplinary effort (Fazio and Galeazzi, 2004). However, the findings of this study can not be generalised because it was conducted in one country, Italy, which has a different culture than the UK, and because the study population included only female victims.

To extend these results, using case scenarios, the Modena Group on Stalking (MGS) conducted a study in three European countries to examine the awareness and recognition of stalking by police and GPs as they represented the first line of professionals contacted by victims (Fazio and Galeazzi, 2004). Researchers attempted to examine recognition and attitudes among GPs and police officers in a cross-national study in the European Union (Kamphuis et al., 2005). The researchers used case scenarios and standardised questions,

and found that differences in responses depended on the country, profession and personal subjectivity (Kamphuis et al., 2005). Abnormal behaviour could be identified by the GPs, and to less extent among police officers, which is in line with the findings of Fazio and Galeazzi (2004). Subjective differences among GPs and police officers were also observed, such as considering stalking as a flattering relatively harmless behaviour and blaming the victim, but GPs in the UK in comparison to police officers and GPs in other EU countries showed less individual variations and blaming victims (Kamphuis et al., 2005).

Furthermore, the researchers assumed that exploring real stories told by victims give more useful information. Thus, the MGS explored the experiences of stalking victims in the EU, reporting results from Belgium, Italy and Slovenia (Galeazzi et al., 2009). Researchers from the UK, Belgium, Italy, Netherlands, Slovenia and Spain took part in this study and data was collected in the context of a research project sponsored by the European Commission Daphne Research Programme. The online survey was available at the website in five languages and advertised via the press, radio and in collaboration with agencies to support victims. Out of the 391 included participants, 80.9% were females and they were aged between 15 to 64, with a mean age of 29.2 years. The study revealed that 78.8% of the cases included phone calls, 57% texting SMS, 26.6% sending emails, with 13.8% contacting the person via the Internet. With regards to the impact, 48.6% of the victims reported extreme levels of fear, 39.4% of participants had a low WHO wellbeing index, and 70.1% had a high score of general health questionnaire indicating clinical health consequences. Most victims looked for support from family and friends (86.7%), followed by colleagues (42.5%) and the police (42.5%). Of those who contacted healthcare professionals, 25.1% contacted GPs, 19.7% communicated with mental health professionals, and only 14.8% contacted victim support groups (Galeazzi et al., 2009). The perceived quality of help received from victims' perspectives varied, mental health professionals were on the top of the list followed by family and friends, lawyers, victims support groups, colleagues, GP, social support groups and lastly,

the police. With regard to the perception of being taken seriously, GPs were ranked fourth after mental health professionals, lawyers and family. The police were in last position on the list, this was partly explained by reasons related to not being taken seriously, stalking had stopped or when victims felt it was not a police issue or they could do nothing about it. Regarding the perceived effectiveness of intervention provided by these groups, GPs were ranked last, with the police, victim support groups and mental health professionals also ranking low down on the list compared to family, friends and lawyers (Galeazzi et al., 2009).

The assumed role of healthcare professionals in the self-management of chronic diseases is to educate and explain to patients (Greenhalgh, 2009). This is challenging in the case of cyber-victimisation because GPs recognise the problem, but do not provide effective support (Galeazzi et al., 2009). This highlights the importance of exploring GPs' encounters with cyber-victimisation victims and providing health promotion tools to increase the awareness of this issue. This is supported by previous findings, where victims felt being taken seriously by agencies would help them, which could be though increasing awareness on stalking and getting practical advice (Sheridan, 2005). A possible challenge to address this issue in the UK is the limited participation by GPs. In the MGS research, the response rate was lower among GPs compared to police officers, and low in the UK compared to other EU countries. GPs in the UK stated that they were supportive of the research, but because the methodology was overextended, they did not complete it (Kamphuis et al., 2005). Accordingly, GPs limited time has an influence on their responses to research, which should be considered.

2.4 Systematic review

2.4.1 Rationale for the systematic review

In addition to the rationale discussed in section 1.1, further synthesis of evidence was required to support this research. Previous reviews focused either on cyber-victimisation

experiences (Selkie, Fales and Moreno, 2015; Foody, Samara and Carlbring, 2015), coping with cyber-victimisation by apparently healthy individuals (Raskauskas and Huynh, 2015), offline victimisation (Nocentini, Zambuto and Menesini, 2015), comparing both offline and online victimisation (Zych, Ortega-Ruiz and Del Rey, 2015; Della Cioppa, O'Neil and Craig, 2015; Vivolo-Kantor et al., 2014), or describing online experiences and health consequences (Daine et al., 2013). Hence, no special focus was given to people with chronic conditions and disabilities.

Reviews focusing on chronic conditions or disabilities addressed offline victimisation of people with disabilities (Maïano et al., 2015; Mikton, Maguire and Shakespeare, 2014), supporting general knowledge on people with disabilities (Seewooruttun and Scior, 2014) or looked at the impact (Sentenac et al., 2011a) on a range of conditions. However no review focused on the issue of cyber-victimisation of people with chronic conditions or disabilities and its impact on them. This review was conducted and published in a high impact peer reviewed journal as stated in section 6.3.3.

2.4.2 Systematic review methods

The targeted population comprised individuals with chronic conditions and/or disabilities, regardless of age, gender, ethnic background or country. The intervention included any form of cyber-victimisation, defined here as a negative communication initiated by the “offender” towards the “victim” and involving an electronic means (Kouwenberg et al., 2012; Maple, Short and Brown, 2011). Internal comparisons were based on the type of condition or the nature of the cyber-victimisation. The primary anticipated outcomes were the frequency of cyber-victimisation and the impact on the study population (medical, psychological and personal). The secondary outcome was the connection, if any, between having a chronic condition and being targeted. Eligibility criteria included peer-reviewed studies published between January 1990 and January 2016. Employing any study design, these papers targeted people with

chronic conditions and/or disabilities or included them as part of the study sample, and reported cyber-victimisation scope and its direct or indirect impact. It should be noted that data extracted for this review is exclusive to people with chronic conditions and disabilities.

2.4.2.1 Search strategy

Several information sources were searched (PubMed, Embase, PsycINFO, CINAHL, and Cochrane), in addition to snowballing of references as shown Figure 1. The search strategy was based on three components: 1) keywords related to cyber-victimisation, 2) keywords related to chronic conditions and disabilities, and 3) specific conditions with high prevalence or documented relation to victimisation. The search strategy aimed to get any keyword from component 1 with a keyword from either components 2 or 3. The wild card function –Asterisk- was used with the words (victim*, impair*, disabil*) to cover variable spellings and derivatives. It was acknowledged that the synonyms list was essentially long, firstly due to the differences in defining cyber-victimisation (Dreßing et al., 2014; Sheridan and Grant, 2007), and secondly because chronic conditions are addressed in different ways by researchers (Sentenac et al., 2011b; Fridh, Lindström and Rosvall, 2015). The search strategy was piloted with the academic liaison at the University's library. Upon piloting, entering few words to search full texts in databases yielded few results, while including all of the keywords caused page errors. This was overcome by breaking down the search into 4 different rounds (Appendix 9).

2.4.2.2 Selection of studies

Search results (n= 2,915) were first imported and then duplicates were deleted. Titles and abstracts of the remaining 1,873 studies were scanned and 144 potentially relevant studies were listed. The review process was inclusive: the first round included all studies mentioning traditional or offline victimisation to search the full text for a cyber-element,

because early studies in the literature reported cyber-victimisation as part of traditional victimisation. Of these studies, 72 were disqualified due to ineligibility, while 7 papers were added from snowballing, resulting in a total of 79 papers for full-text screening. Papers were screened for inclusion criteria, mainly reporting cyber-victimisation or a disability and/or chronic condition in the study population. To ensure no detail was missed, screening required two stages: first, by reading through the papers and second, by electronically searching for keywords within the papers.

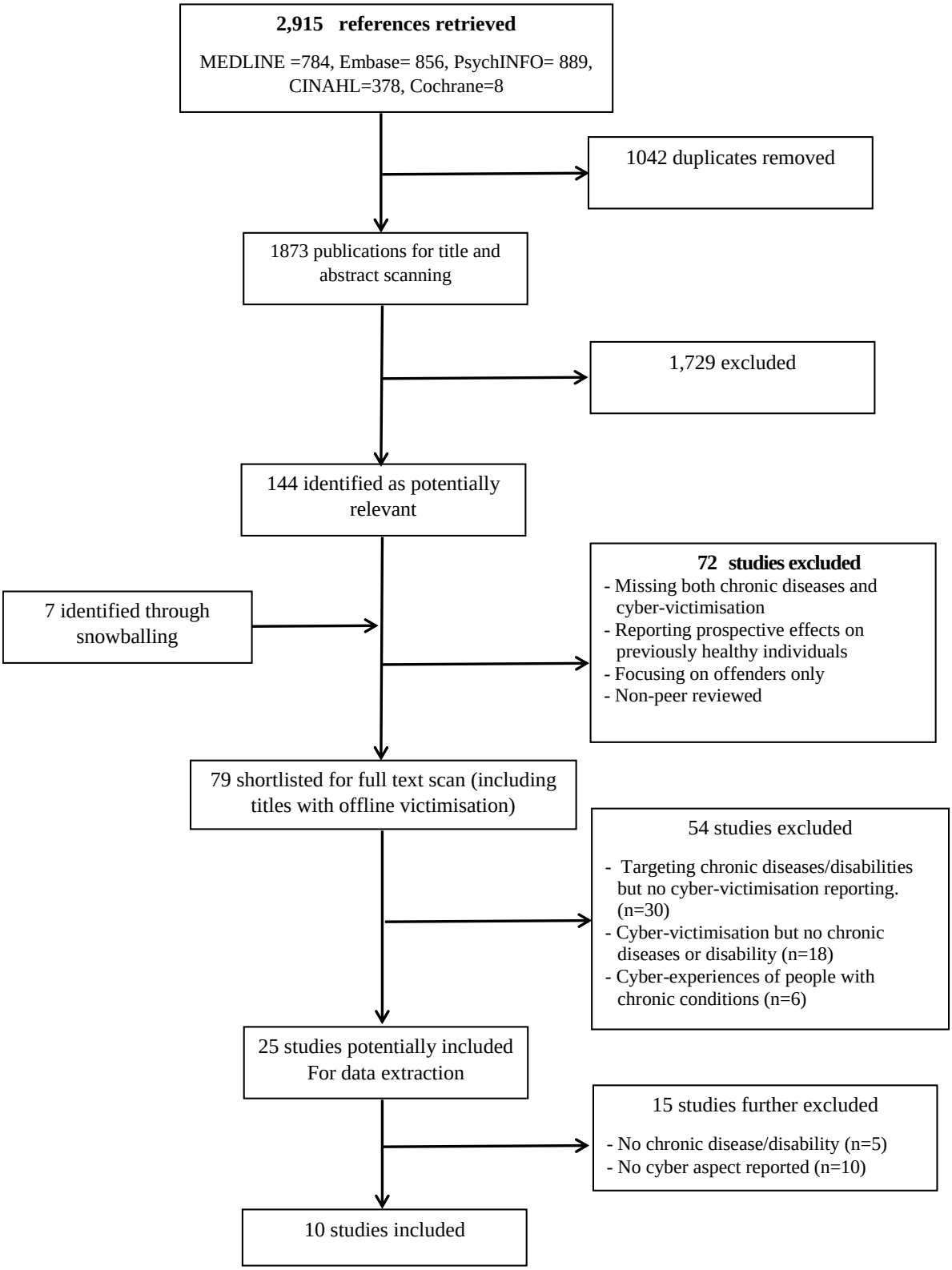

Figure 1. *Flowchart of study selection process*

Of the 79 shortlisted papers, 54 were excluded in total: 30 were not eligible due to focusing on victimisation of people with chronic diseases or disabilities without clear reporting of a cyber-aspect. They focused on victimised people with psychological, psychiatric, neurological, or other impairments, such as intellectual disabilities and autism spectrum disorders (Bitsika and Sharpley, 2014), hearing impairment (Dixon, 2006), endocrine disorders (Devine et al., 2008), epilepsy (Hamiwka et al., 2009), ADHD (Wiener and Mak, 2009), disabilities (Blake et al., 2012), visual impairment (Dane-Staples et al., 2013), and overweight and obese (van Geel, Vedder and Tanilon, 2014). An additional 18 studies were excluded for reporting cyber-victimisation without addressing chronic conditions as part of the sample. Lastly, 6 studies were excluded because their focus was on exploring the online experiences of people with chronic conditions, but the cyber-victimisation aspect was not covered. At the end of this stage, 25 papers were potentially qualified for data extraction. The last round involved detailed reading of the results section: 10 studies were excluded for not reporting cyber-victimisation and 5 studies for not reporting figures specific to people with chronic conditions in the results section despite including them in the introduction and methodology sections. A total of 10 studies were eventually eligible for this review; Figure 1 illustrates the flowchart for the study selection.

2.4.2.3 Quality assessment

The study design for most of the included studies was cross-sectional. The availability of a well-developed comprehensive tool to assess the quality of observational studies, such as cohort, case-control or cross-sectional studies, is limited compared with tools available to assess randomised controlled trials (Von Elm et al., 2007). Furthermore, tools addressing cross-sectional studies in particular are few (Sanderson, Tatt and Higgins, 2007). Authors 1 and 3 in this study looked for specific tools to use for this review. Only one tool (Gyorkos et al., 1994) included cross-sectional design to assess systematic reviews (Sanderson, Tatt and Higgins, 2007), but the comprehensiveness of this tool is limited. Hence, we applied a rigorous

assessment in two stages. In stage 1, quality assessment was informed by the types of bias identified by (Gyorkos et al., 1994), and supported by a critical appraisal tool presented in Fowkes and Fulton (1991), which addresses cross-sectional studies with a summary judgment (Sanderson, Tatt and Higgins, 2007). Studies were rated with ++ when a major problem was identified, + for minor problems, 0 to indicate no problems or NA when the criterion was not applicable. Examples of major problems include sampling issues and eligibility criteria to identify the study population, while minor problems are mainly in reporting outcomes. Due to the relatively new emergence of cyber-victimisation in literature, the authors agreed to investigate the results with an additional tool. Hence, in stage 2, the quality assessment was further cross-checked. In a recent systematic review, a specific tool was developed to assess cyberbullying research; it consists of 21 items with a possible total score of 42 points (Selkie, Fales and Moreno, 2015). Utilised in this review, this tool is a modified and applicable version of the "Strengthening the Reporting of Observational Studies in Epidemiology" (STROBE) Statement (Von Elm et al., 2007). Primarily in stage 2, we further assessed the criteria used to define cyber-victimisation and victim/offender variables, validated instruments used by the researchers and evaluated the overall reporting of cyber-victimisation. Finally, the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2018) checklist was used to assess any qualitative parts in the included studies.

In this review, studies were considered strong when they had no major problems in stage 1 (Fowkes and Fulton, 1991; Gyorkos et al., 1994) and a score of 32–42 in stage 2 (Selkie, Fales and Moreno, 2015; Von Elm et al., 2007). Studies were described as moderate when they had one major problem with a score of 21–31, and considered weak if they had two or more major problems *or* a score of 1–20 (Mikton, Maguire and Shakespeare, 2014). The full assessment was performed by author 1 and sent out to all other authors to review separately. This was followed by discussion among all authors; at this stage, there was a consensus on the final quality assessment results reported in Appendix 5.

2.4.2.4 Data extraction and management.

A data extraction form was prepared and piloted on the included studies. Independent data extraction was initially performed by author 1, which was followed by revision and discussion involving the remaining authors. Although most of the studies adopted a cross-sectional design, they were too heterogeneous in defining outcomes, study population, tools used, types of disabilities and reporting outcomes. Hence, statistical meta-analysis was not performed. Instead, the results were presented in a narrative synthesis. This narrative adopted Petticrew et al. (2009) guidance in developing preliminary synthesis through tabulating data, grouping findings and writing textual descriptions. This was followed by exploring the relationships between studies in terms of study characteristics and findings. Ultimately, the final discussion included the theoretical underpinnings and the quality of the selected studies (Petticrew et al., 2009; Melendez-Torres et al., 2015).

2.4.3 Systematic review results

2.4.3.1 Included studies.

A total of 10 publications were eligible for this review. Included studies could be grouped into four general categories: 1) Victimisation (cyber and traditional) and the impact on health (Annerbäck, Sahlqvist and Wingren, 2014), 2) Victimisation (cyber and traditional) of individuals with chronic conditions/disabilities (Gibson-Young et al., 2014; Mueller-Johnson, Eisner and Obsuth, 2014; Sofronoff, Dark and Stone, 2011), 3) Cyber-victimisation of people with chronic conditions and/or disabilities (Didden et al., 2009; Kowalski and Fedina, 2011; Yen et al., 2014), 4) Cyber-victimisation characteristics or impact (Fridh, Lindström and Rosvall, 2015; Sheridan and Grant, 2007).

2.4.3.2 Quality of included studies

Stage one and stage two of the quality assessment results identified 4 strong studies (Sheridan and Grant, 2007; Mueller-Johnson, Eisner and Obsuth, 2014; Wells and Mitchell, 2014; Fridh, Lindström and Rosvall, 2015), and 6 moderate studies (Didden et al., 2009; Sofronoff, Dark and Stone, 2011; Yen et al., 2014; Gibson-Young et al., 2014; Annerbäck, Sahlqvist and Wingren, 2014; Kowalski and Fedina, 2011). Quality assessment scores for both stages are summarised in Table 1, and the implications of identified issues will be further addressed in the discussion section.

In stage one (Fowkes and Fulton, 1991; Gyorkos et al., 1994), no paper had more than one major problem, four studies had one major problems, these were: sample size, not reporting response rate or explaining the inclusion criteria (Kowalski and Fedina, 2011); study population were only parents (Sofronoff, Dark and Stone, 2011); no comparator group reported (Yen et al., 2014), and partial reporting of outcome in relation to chronic diseases (Annerbäck, Sahlqvist and Wingren, 2014). Other non-major problems were identified in the remaining papers, as reported in Table 1.

In stage two (Selkie, Fales and Moreno, 2015; Von Elm et al., 2007), included studies scored a range of 20-40 points. The scores ascertained the issues identified in stage 1 and added to them specific issues related to cyber-victimisation reporting. CASP list was used to assess the qualitative element reported by Sofronoff, Dark and Stone (2011). It was judged to be intermediate for two reasons. Firstly, the endorsement of the cyber-victimisation theme was not sufficient to draw conclusions. Secondly, the qualitative research ethics and power relations were under-reported.

2.4.3.3 Study characteristics.

Most of the included studies (n=9) adopted a pure quantitative approach employing a cross-sectional design. While one study (Sofronoff, Dark and Stone, 2011) adopted a mixed-method design consisting of a cross-sectional element, and focus groups with thematic analysis. Appendix 6 summarises studies' characteristics.

Target population. A total of 3,070 people with chronic conditions were reported across all included studies. Sample size ranged between 42 and 823 participants, whose ages ranged between 6 and 71 years. Examining or targeting individuals with chronic conditions or disabilities was the primary aim of seven studies (Kowalski and Fedina, 2011; Didden et al., 2009; Sofronoff, Dark and Stone, 2011; Mueller-Johnson, Eisner and Obsuth, 2014; Wells and Mitchell, 2014; Yen et al., 2014; Gibson-Young et al., 2014). However, one of these studies included parents of participants as part of the sample (Yen et al., 2014) and in another study, parents comprised the whole sample to reflect on the experiences of their children (Kowalski and Fedina, 2011). People with disabilities were not the primary target population in two studies (Annerbäck, Sahlqvist and Wingren, 2014; Fridh, Lindström and Rosvall, 2015). One study (Sheridan and Grant, 2007) primarily targeted self-identified victims of stalking and disability emerged from the findings.

Recruitment. Participants were recruited from public schools (Gibson-Young et al., 2014) (Sofronoff, Dark and Stone, 2011; Annerbäck, Sahlqvist and Wingren, 2014), schools for special education (Didden et al., 2009; Wells and Mitchell, 2014), summer camps for people with disabilities (Kowalski and Fedina, 2011), telephone-based interviews (Wells and Mitchell, 2014), or from a clinical setting (Yen et al., 2014). The study populations were drawn from nationally representative samples in five studies (Mueller-Johnson, Eisner and Obsuth, 2014; Wells and Mitchell, 2014; Gibson-Young et al., 2014; Annerbäck, Sahlqvist and Wingren,

2014; Fridh, Lindström and Rosvall, 2015). Sheridan and Grant (2007) employed national and international media for the recruitment of 1051stalking victims.

Sample diversity. Gender distribution among participants with chronic conditions was reported in five studies with clear variation. One study showed close figures of 57.1% males and 42.9% females (Kowalski and Fedina, 2011). Other studies reported the sample being mostly males: 72% males (Didden et al., 2009), 86.4% males (Sofronoff, Dark and Stone, 2011), 100% males (Yen et al., 2014). The numbers reported in the remaining studies were not specific to the population with chronic conditions.

Ethnicity was reported specifically for people with chronic conditions in two studies (Kowalski and Fedina, 2011; Didden et al., 2009), with the majority of participants having a white ethnic background. Two studies (Sofronoff, Dark and Stone, 2011; Yen et al., 2014) did not report ethnicity, while the rest of the studies reported numbers that were not specific to the population with chronic conditions.

2.4.3.4 Cyber-victimisation.

There was a range of definitions and terminologies used to identify cases of cyber-victimisation as shown in Appendix 7. The highest reported prevalence of cyber-victimisation of people with chronic conditions was 41.7% (Fridh et al., 2015) and the lowest was 2% (Didden et al., 2009). Two estimates in this range were different in the form of presenting outcomes; Sofronoff, Dark and Stone (2011) reported cyber-victimisation as a theme endorsed by 2.4% of victims' parents out of 82 responses. Sheridan and Grant (2007) found that 11.9% of people who purely experienced cyberstalking (4% of sample) stated being disabled when asked about their occupation.

Included studies were inconsistent in the timeframe use to identify cyber-victimisation. Incidents were associated with variable durations such as lifetime prevalence (Mueller-

Johnson, Eisner and Obsuth, 2014), past year prevalence (Wells and Mitchell, 2014; Yen et al., 2014; Gibson-Young et al., 2014; Fridh, Lindström and Rosvall, 2015), or once in 2 months (Kowalski and Fedina, 2011; Annerbäck, Sahlqvist and Wingren, 2014). Alternatively, Didden et al. (2009) broke down the frequency to be either one incident within 3 months via a cell phone, or a minimum of one occurrence a month via the Internet. While Sheridan and Grant (2007) specified a minimum duration of 4 weeks and 10 occasions to identify cyberstalking.

2.4.3.4 Chronic conditions

The included studies adopted variable criteria to identify patients as well as different terminologies to address their conditions, as shown in Appendix 8.

Chronic conditions were mainly psychological, psychiatric or developmental, such as Asperger's syndrome (Sofronoff, Dark and Stone, 2011) and ADHD and Asperger's syndrome (Kowalski and Fedina, 2011). Didden et al. (2009) reported a similar category of conditions, which were broken down into 82% intellectual disabilities or borderline IQ, and 18% developmental or emotional disability; 67% of the sample had a previous diagnosis of ADHD or pervasive developmental disorder (PDD). Yen et al. (2014) included ADHD, oppositional defiant disorder (ODD), conduct disorder, tic disorder and autism. The same study excluded people with intellectual disability, schizophrenia, bipolar disorder or autistic disorder with difficulty to communicate or having cognitive impairment. Fridh, Lindström and Rosvall (2015) adopted a detailed list of conditions, but these were mainly psychiatric or neurological conditions. The list covered impaired hearing, impaired vision, reading/writing disorders, dyslexia, ADHD and ultimately provided an option called "other" for conditions not listed. Mueller-Johnson, Eisner and Obsuth (2014) focused purely on physical disability, either congenital or secondary to an illness or an accident. The sample addressed by Wells and Mitchell (2014) comprised individuals with special education needs, physical disability or a combination of both.

Diseases affecting other physiological systems were less frequently documented. Gibson-Young et al. (2014) focused solely on asthma patients. A more detailed list of chronic diseases was covered by Annerbäck, Sahlqvist and Wingren (2014). It included asthma, diabetes, epilepsy, impaired hearing, visual impairment, motor dysfunction, dyslexia, ADHD, allergy, intestinal diseases and obesity. However, Annerbäck, Sahlqvist and Wingren (2014) reported the results of all these conditions collectively and no participant in the sample had obesity.

2.4.3.5 The impact of cyber-victimisation

Five studies (Kowalski and Fedina, 2011; Didden et al., 2009; Yen et al., 2014; Gibson-Young et al., 2014; Fridh, Lindström and Rosvall, 2015) reported complications specific to cyber-victimisation, while four studies (Sofronoff, Dark and Stone, 2011; Wells and Mitchell, 2014; Annerbäck, Sahlqvist and Wingren, 2014; Sheridan and Grant, 2007) addressed cyber-victimisation consequences partially or as part of victimisation experiences in general. One study (Mueller-Johnson, Eisner and Obsuth, 2014) highlighted the impact of online sexual victimisation without providing explicit findings.

The impact of cyber-victimisation was measured using a predetermined set of questions that focused mainly on psychological complications. The most commonly documented issue was depression (Kowalski and Fedina, 2011; Didden et al., 2009; Yen et al., 2014; Wells and Mitchell, 2014; Gibson-Young et al., 2014; Annerbäck, Sahlqvist and Wingren, 2014; Sheridan and Grant, 2007), followed by anxiety (Kowalski and Fedina, 2011; Sofronoff, Dark and Stone, 2011; Yen et al., 2014; Annerbäck, Sahlqvist and Wingren, 2014; Sheridan and Grant, 2007) and suicide or self-harm (Yen et al., 2014; Annerbäck, Sahlqvist and Wingren, 2014; Sheridan and Grant, 2007). Relatively less common problems were low self-esteem (Kowalski and Fedina, 2011; Didden et al., 2009), behavioural issues (Sofronoff, Dark and Stone, 2011) and

substance abuse (Wells and Mitchell, 2014). It is worth noting that distress was statistically significant in cyber-victimisation cases (Wells and Mitchell, 2014).

Two studies (Annerbäck, Sahlqvist and Wingren, 2014; Fridh, Lindström and Rosvall, 2015) reported more detailed physical and mental health-related variables. Annerbäck, Sahlqvist and Wingren (2014) used a comprehensive list of health indicators, which included poor general health, physical health problems (headache, migraine, stomach ache, tinnitus, musculoskeletal pain), mental health problems (insomnia, anxiety, worry, depression) and self-injurious behaviour. In comparison, Fridh, Lindström and Rosvall (2015) addressed a group of general symptoms called “subjective health complaints”. Participants’ health status was determined through responses to questions on headache, feeling low, irritability, nervousness, sleep disturbances and dizziness.

The impact of cyberstalking was covered by Sheridan and Grant (2007), who concluded that well-being and economic consequences were comparable to the effects of traditional stalking. Further, significant differences specific to cyberstalking included the emergence of international perpetrators, threats of physical assault on the victims or people close to them, the need to change email addresses and loss of social relations (Sheridan and Grant, 2007).

There were variations in comparators used to study cyber-victimisation impact. The most common approach (n=5) was comparisons with people not having disabilities (Wells and Mitchell, 2014; Mueller-Johnson, Eisner and Obsuth, 2014; Annerbäck, Sahlqvist and Wingren, 2014; Fridh, Lindström and Rosvall, 2015) or without a particular diseases (Gibson-Young et al., 2014).

Some internal comparisons considered gender differences. Subjective health complaints were significantly higher in cases of cyber-harassment especially among female victims (Fridh, Lindström and Rosvall, 2015). Cyberbullying caused significant poor general

health in males compared to no abuse comparator, physical health was significantly poorer in females, and mental health was poor in both genders (Annerbäck, Sahlqvist and Wingren, 2014).

The alternative approach was selecting internal comparators based on the type of offence, victim status, or the method used. Comparing traditional offences with cyber ones was covered in cases of cyberbullying (Kowalski and Fedina, 2011) and cyberstalking (Sheridan and Grant, 2007). Victim status was examined as a "victim/no victim" (Annerbäck, Sahlqvist and Wingren, 2014) or being a "victim and/or a bully" (Didden et al., 2009). Additionally, no comparator was reported by Yen et al. (2014) apart from partially contrasting the impact on victims and offenders, concluding that depression and suicidal ideation or attempts were more severe in victims. Victimisation methods via cell phone or the Internet were distinguished in one study (Didden et al., 2009). Lastly, Sofronoff, Dark and Stone (2011) compared the findings to a standardised population but cyber-victimisation emerged only as a theme, hence no further conclusions could be drawn.

2.4.3.6 Relation between chronic conditions and cyber-victimisation

The risk of being targeted was the main acknowledged link between having a chronic condition and being cyber-victimised (Sofronoff, Dark and Stone, 2011; Mueller-Johnson, Eisner and Obsuth, 2014; Annerbäck, Sahlqvist and Wingren, 2014; Wells and Mitchell, 2014; Gibson-Young et al., 2014; Fridh, Lindström and Rosvall, 2015). Vulnerability here implies the higher risk of discrimination against people with long-term conditions. It was linked by Sofronoff, Dark and Stone (2011) specifically to social vulnerability, while it was used by Fridh, Lindström and Rosvall (2015) as a covariate, and found to be specific to cases of cyber-harassment. Some studies (n=3) looked at the vulnerability of victims and offenders at the same time, and concluded that the impact was higher on victims (Kowalski and Fedina, 2011; Didden et al., 2009; Yen et al., 2014). An explanation of this higher risk was suggested by

Sheridan and Grant (2007) who considered the longer time spent online due to disability as a potential risk factor for victimisation.

2.4.3 Discussion of systematic review results

2.4.3.1 Gaps in methodology

The cross-sectional design adopted in almost all of the included studies could have undermined the exploration of the impact of cyber-victimisation. This inflexible design offers a limited set of options to participants, and hence it does not fully address issues arising during the research process. This is especially important in the cases where the data was drawn retrospectively from an existing data set (Mueller-Johnson, Eisner and Obsuth, 2014). Exploring the lived-experience by employing a qualitative approach could be more informative. However, only one paper with a qualitative element was included (Sofronoff, Dark and Stone, 2011), and it had a major issue in the quality assessment because the participants were the parents of victims. Including parents as informants was considered a limitation in traditional victimisation research (Blake et al., 2012). Further, parents might be less aware of their children's online behaviour in the case of cyber-victimisation (Annerbäck, Sahlqvist and Wingren, 2014). Hence, a phenomenological approach that takes input from victims themselves as experts in their experiences could address this gap.

Some of the excluded studies employed qualitative methods with victims. Mishna, McLuckie and Saini (2009) looked at the lived-experience with a phenomenological approach, but the focus was not on people with chronic conditions. Weight-based victimisation was mentioned briefly in the findings without providing details. Additionally, another excluded qualitative study had addressed appearance-related victimisation (Berne, Frisén and Kling, 2014). Although excluded, these studies could be relevant, because many chronic conditions

have appearance-related symptoms that put people coping with them potentially at a higher risk of victimisation. Hence, considering other research designs in the future is recommended.

2.4.3.2 The influence of diversity on results

Gaps in researching age, ethnicity and gender were identified. These gaps should also be considered during the practical assessment of cases and in policy, in which careful consideration of the interconnections between diversity elements is recommended.

Although the age range in this review was between 6 and 71 years, only one study (Sheridan and Grant, 2007) had participants over 20 years of age, and in this study, disability emerged incidentally rather than being a primary outcome. Hence, the impact on younger people was extensively examined compared to adults. It is evident that both traditional victimisation (McGrath, Jones and Hastings, 2010) and cyber-victimisation (Sheridan and Grant, 2007) have an impact on older people, too. Thus, inclusivity in addressing older people is indicated.

The majority of participants in the included studies came from a white ethnic background. This could be due to the context of the study, taking nationally representative samples, or because of higher reporting by people with a white ethnicity (Maple et al., 2012). However, ethnicity plays a role in hate offences and in biologically-related health complications, which necessitates further exploration.

In terms of gender, samples in studies that looked particularly at people with disabilities were male-dominated. The exception was the study by Kowalski and Fedina (2011), although we cannot draw conclusions because the sample size remains an issue in the quality assessment. Although this dominance might reflect the prevalence of included conditions in males such as ADHD (Yen et al., 2014), this might not represent cyber-victimisation accurately.

The role of gender in cyber-victimisation research is variable. When considering victim status, it was found to be more common in females (Sheridan and Grant, 2007) but this is not a consistent finding in the literature (McGrath, Jones and Hastings, 2010). Some studies found cyber-victimisation higher in males (Fridh et al., 2015), while others found no correlation with gender (Didden et al., 2009). However, the examination of impact revealed significant health complaints secondary to cyber-victimisation among females (Fridh, Lindström and Rosvall, 2015). This confirms previous research when girls with ADHD were included only, and there were significant victimisation and social problems (Sciberras, Ohan and Anderson, 2012). These discrepancies in the results and the literature demonstrate how the relationship between gender, disability and cyber-victimisation requires further investigation.

2.4.3.3 The prevalence of cyber-victimisation

The wide prevalence range of cyber-victimisation in this review could have been influenced by the definition, criteria and instruments adopted in each study. For example, utilising validated tools that had not been updated to include questions on the cyber aspect (Solbergn and Olweus, 2003; Rigby and Slee, 1993) could have possibly led to an underestimation in numbers (Kowalski and Fedina, 2011) or themes (Sofronoff, Dark and Stone, 2011). In addition, the use of old tools could have caused the unintentional exclusion from this review of cases where cyber-victimisation was acknowledged by authors but not clearly incorporated in the research instruments (McGrath, Jones and Hastings, 2010; Chen and Schwartz, 2012; Wiener and Mak, 2009; Sentenac et al., 2013).

The duration adopted by researchers to identify cases could also have influenced the reported frequency. Cyber harassment prevalence of 47.5% dropped down to 7.2% when strict criteria were applied to identify cyberstalking cases (Sheridan and Grant, 2007). The highest reported cyber-victimisation prevalence was 41.5% (Fridh, Lindström and Rosvall, 2015), which could be due to concurrently mentioning social media in questions asked, taking the

past year's prevalence into account and covering a long list of conditions. The study by Mueller-Johnson, Eisner and Obsuth (2014) is another example of examining the past year prevalence's, but their focus on physical disabilities might have limited the prevalence, which was still as high as 23.5%. The highest prevalence was documented by Fridh, Lindström and Rosvall (2015) and could be a reflection of a growing trend of higher estimates in the more recent studies, which is alarming considering the impact endured by victims who are already coping with their health conditions.

The terminology used varied: cyberbullying, which involves power imbalance, was the most commonly used term, especially considering that most of the studies focused on young victims. In cases of targeting people with disabilities, the "right" term might not be clear. With regard to power differences, people with long-term conditions are considered at risk of being targeted (Office of the Public Guardian, 2017; Levine et al., 2004). This risk is further confirmed by the higher risk of victimisation seen in both traditional (Sentenac et al., 2011a) and cyber offences (Annerbäck, Sahlqvist and Wingren, 2014). Hence, it could be argued that the term "cyberbullying" could be applied to this group irrespective of age or context. However, cyberstalking, which is characterised by persistence, can also be seen in cases of disability hate crimes in which victims had experienced repetitive harassment from similar groups (Richardson et al., 2016). This could be the reason disability was overrepresented in pure cyberstalking cases (Sheridan and Grant, 2007). Cyber-victimisation or cyber-harassment (Fridh, Lindström and Rosvall, 2015; Sheridan and Grant, 2007) were used as umbrella terms, making them relevant to people with chronic conditions, too. Accordingly, all terminology applied in the included studies could be justified. However, consistency in defining cyber-victimisation of this specific group in future research might help to connect international and interdisciplinary literature, and to communicate with support channels to address the impact efficiently.

Despite the acknowledged differences in definitions, the higher risk of being targeted was a consistent finding, mainly being at risk due to being “different” physically, intellectually or in lifestyle (Annerbäck, Sahlqvist and Wingren, 2014). This was confirmed against different comparators (Fridh, Lindström and Rosvall, 2015; Wells and Mitchell, 2014). Additionally, in some cases it was linked with the time spent online which could imply victim-blaming. Hence, this finding advocates collaborative action to support victims.

2.4.3.4 Chronic diseases, disabilities and impact

Most of the studies covered conditions related to intellectual or physical impairment. Only two studies focused on other chronic diseases such as asthma (Gibson-Young et al., 2014) or included diabetes, epilepsy and intestinal diseases (Annerbäck, Sahlqvist and Wingren, 2014). The criteria used to identify people with chronic conditions or disabilities had a potential role in directing the results, in addition to disciplinary variations. The reporting of detailed health complications was seen when health questionnaires were employed in studies carried out in the public health discipline (Fridh, Lindström and Rosvall, 2015; Annerbäck, Sahlqvist and Wingren, 2014). First, this strengthens the argument on the gap in methodology and how the cross-sectional design had influenced the representation of issues, as discussed earlier. Second, it raises questions whether excluded studies, which looked at the victimisation of other conditions such as endocrine disorders (Devine et al., 2008) or epilepsy (Hamiwka et al., 2009), could have achieved similar results if researched from a cyber-perspective. The implication of this illustrates the need for scoping cyber-victimisation in a broader range of conditions with flexibility of input from participants.

Another issue in identifying conditions was seen in the terminology used; most of the included studies used the term “disability” to refer to a heterogeneous group of conditions. Defining disability is a documented challenge between researchers and across countries

(Blake et al., 2012). This undermines the impact reported in this review and highlights the need to recognise the wide range of conditions that exist.

Psychological or psychiatric consequences were the most commonly reported complications of cyber-victimisation, mainly depression followed by anxiety and distress. This could be overlooking other underreported complications in case these figures were influenced by the type of conditions included, discipline or methodology, as discussed earlier. Psychological consequences are consistent with previous research on cyber-victimisation, such as depression, guilt, shame, and self-harm (Short et al., 2015b). Additionally, depression is a common complaint in primary care, a major cause of morbidity and a leading cause of suicide with higher challenges when associated with other conditions (Semple and Smyth, 2009). Thus, with acknowledging the seriousness of depression and/or distress as a major impact resulting from cyber-victimisation, it still requires further research based on each condition because of the heterogeneity of chronic conditions.

To illustrate these differences, both Gibson-Young et al. (2014) and Yen et al. (2014) reported depression and had comparable past year prevalence of cyber-victimisation in the same year, with acknowledged differences in demographics. Gibson-Young et al. (2014) looked particularly at people with asthma, while Yen et al. (2014) looked at a set of intellectual and physical disabilities. The daily management in asthma leads to differences from peers and subsequently victimisation, depression and forgoing activities (Gibson-Young et al., 2014). In the case of asthma, self-management requires a specific lifestyle, such as daily monitoring to control attacks, avoiding triggers and adherence to medications (Newman, Steed and Mulligan, 2004; Sentenac et al., 2011a). People with physical or intellectual disabilities also require coping with physical and social obstacles in their schools or communities (Richardson et al., 2016; Kowalski and Fedina, 2011). Hence, cyber-victimisation in both conditions, asthma and intellectual disabilities, is devastating, but developing depression in these two conditions has pathophysiologically different consequences (Short et

al., 2014). In asthma, it could be more immediate due to the pathophysiology of bronchoconstriction triggered by neurohormonal changes (Vig, Forsythe and Vliagoftis, 2006). Additionally, long-term consequences of anxiety and depression result in poor asthma control (Ciprandi et al., 2015), poor quality of life and hospitalisation (Urrutia et al., 2012),whereas in cases of intellectual disabilities, depression and anxiety could present as longer-term complications with challenging clinical presentations and self-harm (Hurley, 2006).

This argument could be further supported by considering the documented traditional victimisation of other chronic conditions such as diabetes (Sentenac et al., 2011a), which is recognised to be associated with depression (Stoop et al., 2015). Another example is the exacerbation of symptoms because of psychosocial stress in chronic tic disorders (Zinner et al., 2012). Depression has different consequences on these conditions as well, due to the underlying physiological variation. Accordingly, the recognition of depression in patients with chronic conditions is a serious challenge (Menear et al., 2015; Hurley, 2006). These potential differences in following up depression as a complication of cyber-victimisation indicate the need of future research to understand specific experiences and provide tailored support.

In addition to psychological consequences, somatic health complaints were also reported as complications of cyber-victimisation (Sheridan and Grant, 2007; Fridh, Lindström and Rosvall, 2015; Annerbäck, Sahlqvist and Wingren, 2014). These effects are comparable with the impact of traditional victimisation in the literature (Sentenac et al., 2013). However, these symptoms, such as headache, fatigue and gastrointestinal upset, are non-specific health complaints that could present in primary care and, without sufficient background, the source of the problem could be missed in practice. This supports the calls to consider cyber-victimisation as a public health concern (Annerbäck, Sahlqvist and Wingren, 2014; Fridh, Lindström and Rosvall, 2015) and necessitates rigorous research to address cyber-victimisation impact on various conditions (Sheridan and Grant, 2007; Wells and Mitchell, 2014). The implication of this point on practice lies in the realisation of the role of healthcare

professionals in identifying cases (Yen et al., 2014; Annerbäck, Sahlqvist and Wingren, 2014), in addition to the need for public education on chronic conditions and cyber-victimisation (Gibson-Young et al., 2014). The provision of such information to both professionals and the public could be seen as a type of social support that is proactive in counteracting the impact upon victims (Fridh, Lindström and Rosvall, 2015).

2.4.4 Summary of the systematic review

This systematic review aimed at scoping the experiences of cyber-victimisation of people living with chronic conditions or disabilities and examine the documented impact on them. Following a four-stage search strategy in several databases including MEDLINE, Embase, PsychINFO, CINAHL, Cochrane and snowballing of references, a total of 2,922 studies were scanned and 10 studies were eventually eligible to be included. Quality assessment was done in two phases using tools specific to observational studies and cyber-victimisation research. A narrative synthesis of reported results covered a total of 3,070 people with chronic conditions from all included studies. Sample size ranged between 42 to 823 participants, and the age range was 6-71 years with a majority of participants being from White ethnic backgrounds. Most studies (n=9) were cross sectional, in addition to one mixed-method study. The prevalence range of cyber-victimisation was 2%-41.7% based on variable definitions, duration and methods. Targeted conditions included physical impairments, intellectual disabilities and specific chronic diseases. The most common documented impact was psychological/psychiatric, mainly depression followed by anxiety and distress. Somatic health complaints and self-harm were also reported. People with chronic conditions and disabilities were consistently at higher risk of victimisation compared with different comparators.

2.4.5 Implications of the systematic review

Conducting this systematic review helped to map a serious issue with potential escalation due to the growing use of technology in communication. This scoping of prevalence and impact revealed the direct and indirect work done so far to address both cyber-victimisation and chronic conditions. The review linked the work done across disciplines and provided a background to guide future research and practice. It could be concluded that cyber-victimisation of people with chronic conditions is a serious and prevalent issue, which has been well documented, with severe complications on several levels. Methodological gaps exist, and further research targeting a broader range of conditions while considering specific complications for each health condition is recommended. Implications for practice point to the role of healthcare professionals in grasping the challenging clinical presentation of such cases and the need for targeted training and raising awareness.

2.4.5.1 Implications on this study

The systematic review provided a supportive background and identified gaps in literature in terms of study design and accountability to the lived experience. In terms of methodology, it identified gaps in researching older age groups. It also highlighted the differences in identifying chronic conditions and its implications on inclusion criteria, which could influence the documented impact. This supported the development of definitions adopted in this research (section 3.3.1.2). The review also identified differences in defining cyber-victimisation categories, hence the term cyberstalking was substituted with an umbrella term to respond to these differences. Additionally, the gap in studies in the UK was recognised, which could be used to communicate this study's findings to stakeholders. This review highlighted the theoretical perspectives in this area which contributed to developing the conceptual framework of this study.

2.5 Theoretical framework

In order to reach a comprehensive theoretical framework to guide this study and help in achieving credible results, several relevant concepts and theories were considered. In the systematic review above that examined the cyber-victimisation of people with long-term conditions and disabilities, theory was reported as a secondary outcome (Alhaboby et al., 2017b). Among the ten included studies, only four papers discussed the experiences of cyber-victimisation through the application of theoretical explanations (Kowalski and Fedina, 2011; Sofronoff, Dark and Stone, 2011; Yen et al., 2014; Fridh, Lindström and Rosvall, 2015).

The most documented approach in cyber-victimisation studies employed the Theory of Mind to explain discrimination experiences of people with disabilities. Kowalski and Fedina (2011) adopted the Theory of Mind and attempted to explain cyberbullying of young people with disabilities. This was through discussing a claimed deficit in social skills in people with ADHD and Asperger's syndrome, which supposedly undermines self-integration with communities. The same theory was addressed by Sofronoff, Dark and Stone (2011), who discussed the victimisation of young individuals with Asperger's syndrome in the light of social vulnerability and constructs of social intelligence. Two constructs were considered as underlying factors for victimisation: 1) gullibility, which is defined as vulnerability to being tricked; and 2) credulity, which is the tendency to believe something (Sofronoff, Dark and Stone, 2011). This resulted in framing victimisation experiences socially and, in some cases, it was argued that misunderstandings in building online relationships resulted in people with disabilities being labelled as offenders and victims at the same time (Yen et al., 2014). Nonetheless, the Theory of Mind was not adopted in this research because, in this sensitive research, it rather implies a victim-blaming approach where the participants could be blamed for being targeted, and this does not align with this research's aim in prioritising the experiences from participants' perspectives and initiating change rather than affirming differences.

Another theory documented in the field was the Reinforcement Sensitivity Theory (Gray, 1970). According to this theory, anxiety could be seen as a response to expected punishment in a situation, and enjoying the situation as a reward. Yen et al. (2014) adopted this theory to examine cyber-victimisation among people with disabilities and the impact of victimisation on self-esteem. However, this approach was not adopted in this study because it was perceived to be focusing on explaining the victimisation from the offender's perspective, and could potentially result in labelling the participants as offenders too.

Social Identity Theory (Tajfel, 2010; Turner, Brown and Tajfel, 1979), was considered at early stages in this research. It examines the development of personal identity, social identity, and subsequent group membership. According to this theory, people categorise themselves to an 'in-group' and an 'out-group', 'us' versus 'them', which is usually accompanied by comparison and bias towards own group. This theory was not directly adopted in cyber-victimisation research, however, it was a potential approach because it was adopted to work with people from marginalised communities in the UK (McNamara, Stevenson and Muldoon, 2013; Stevenson, McNamara and Muldoon, 2014), and could be used to identify positive factors in a community, such as social ties, to improve wellbeing. Therefore, it was relevant to this research in terms of the sensitivity of the topic, and the need to initiate change to support the participants. In spite of this, Social Identity Theory could inform the study but alone it does not explain the impact of cyber-victimisation, so it was not adopted. At later stages in the study, the theory was relevant to explain the recruitment challenges as discussed in section 3.6.4.

Further to the role of communication in experiencing cyber-victimisation, the role of the participants' social networks was considered from the perspective of social support. Fridh, Lindström and Rosvall (2015) examined the role of social support in the cyber-victimisation of adolescents with long-term conditions. This was explained by two approaches: 1) the main effect model, which views social support as always helpful; and 2) the stress-buffering model, in which the level of social support depends on the level of incident or stress caused (Fridh,

Lindström and Rosvall, 2015). This approach was found to be relevant to this study due to the social impact on individuals who experience cyber-abuse (Maple et al., 2012). However, social support does not entirely explain the impact on people with long-term conditions, hence it was used to inform the theoretical framework as discussed in section 2.5.3.

After considering the concepts and theories discussed above, none of them focused on the impact of the experience, with consideration of the physical and psychosocial aspects of impact, particularly among people with long-term conditions. Consequently, biographical disruption was a more suitable concept to guide this study.

2.5.1 Chronic conditions as 'biographical disruptions'

Once a person is diagnosed with a chronic condition, every aspect of his/her life is susceptible to change (Center for Managing Chronic Disease, 2015). Bury (1982) proposed conceptualising chronic conditions as 'disruptive events' in an individual's life. In order to examine the consequences of being diagnosed with a long-term condition, Bury (1982) interviewed 25 women and 5 men aged between 25 and 54 years at the earliest point of diagnosis to explore the impact of the emerging illness on problem recognition, changes in life, and in relationships. This proposal was a development on what Giddens (1979) described as a 'critical situation' in his discussion of major events that cause disruption to the society, such as wars.

Chronic conditions can be regarded as a form of critical situation at an individual level, hence are described as a 'biographical disruption' (Bury, 1982). This disruption involves three aspects: 1) disruption to thinking of taken for granted, because once the individual is diagnosed with a chronic disease, health and lifestyle can not be taken for granted as compared to the previous state, 2) disruption to explanatory systems which results in rethinking of self and as a result, illness may become part of the persons' biography, and 3)

the response to this disruption by moving resources (Bury, 1982). However, there are challenges against mobilising psychosocial resources and often there is a disruption in social activities with family and friends due to physical impairment or as a result of embarrassment. This was supported by the notion of narrative reconstruction, which was introduced after two years, discussing the changing of the relationship following the development of a chronic condition (Williams, 1984). Another recognised issue is that when the symptoms of chronic illness is prevalent in the population, taking pain as an example of a common complaint, it is a problematic situation to legitimise the illness by others, and many chronically ill patients choose to hide their diagnosis for a while being helped by the insidious onset of chronic disease (Bury, 1982).

The concept of biographical disruption was challenged by Williams (2000) in a critical reflection; biographical disruption was criticised for focusing on newly diagnosed conditions and the uncertainty around it in the individual's life. Consequently, this could mean lacking the account for very young patients who were born with these conditions or were diagnosed with them so early that their condition became the norm (Williams, 2000). That is why further exploration of the concept was recommended to include both ends of the life course. However, Larsson and Grassman (2012) disagreed with this notion. The findings from two large qualitative studies from life course perspective, one of which was prospective and involved interviews of chronically ill patients with visual impairments secondary to diabetes or congenital defects over 30 years from 1981 till 2011 in Sweden, and the other retrospective study included old patients who lived with chronic conditions for a long time, such as multiple sclerosis, poliomyelitis, spinal injuries and gastrointestinal conditions, were supportive of the concept of biographical disruption, further adding that the onset of chronic illness is not the only disruptive event in these patients' lives. It also implied that developing complications and physical impairments during disease progression represent continuous disruptive events,

even if they were expected when the natural course of the disease was known (Larsson and Grassman, 2012).

The concept of biographical disruption was applied to different chronic diseases, such as chronic primary headache including migraine and cluster headache (Lonardi, 2007). Application of this concept showed the disruption to life, family and employment in multiple sclerosis patients in the UK (Green, Todd and Pevalin, 2007), disruption around patients with terminal cancer in the UK (Reeve et al., 2010) and in cases of chronic fatigue syndrome and fibromyalgia among women in Sweden (Asbring, 2001). In these cases, this concept was fit to describe the impact of these conditions, while in conditions that do not have physical symptoms, such as hyperlipidaemia, suggested that biographical disruption takes the form of 'biographical working', because these patients look healthy but are taking medications. This brings the biopsychosocial approach and the diseases-illness-sickness model into this discussion.

2.5.2 Disease, illness or sickness?

The representation of a health condition is usually described using one of the terms, diseases, illness or sickness. However, these terminologies are not similar. One of the earliest proposed conceptualisations was considering the biomedical event as the disease, while the subjective personal experience is the illness, and the social representation of the disease is sickness (Kleinman, 1988). Hence, in terms of Kleinman (1988) descriptions, patients with relatively less physical symptoms experience the disease and the sickness, but not the illness. In a critical discussion on the explanations of diseases, illness and sickness concepts, Boyd (2000) traced the definitions to the dictionary, the description provided were unhelpful due to looking at the three terms as synonyms to each other. This reinforced the existing bias among medical practitioners who were always more adaptive to the notion of the disease being a pathological process, with physical symptoms that could be assessed objectively by doctors

(Marinker, 1975). However, doctors also acknowledge that some diseases are of undetermined origins such as schizophrenia. Boyd (2000) discussed illness in this perspective as an experience of a personal nature, a feeling that often accompanies the disease. The recognised challenge here is where illness is experienced with the absence of disease, and patients, in this case, face the objectivity of doctors. Sickness is the public mode of disease, a role or a status that should be negotiated or entitled to. In modern days, it is mostly related to the legitimisation of diseases in order to get what is perceived as benefits such sick notes (Boyd, 2000). This could be related to why people link value judgements with sickness, where there is a common stereotype to think about once hearing the word ill or disabled. Hence, sickness could be linked with disability entitlement and disability benefits (Emerson and Roulstone, 2014), which can be associated with being targeted as discussed earlier. Thus, some diseases are easily legitimised compared to others; chronic diseases are less legitimised than acute infections. Even when someone has a very minor illness, from medical perspective he/she has a disease, while presenting with psychosomatic symptoms i.e., illness without underlying pathology is more difficult to negotiate with doctors. This is supported by the over-ambitious definition of health by the WHO, which links health to the absence of disease, not illness (World Health Organization, 2005). This might explain why people with chronic conditions, despite having a legitimate diagnosis, hesitate in contacting their doctors when experiencing subjective symptoms following victimisation, as discussed earlier.

The negotiating of identity between illness and sickness was discussed by Lonardi (2007), who incorporated the social element in some cases that are less prevalent, but yet devastating conditions. Lonardi (2007) considered a chronic headache as an illness and a disease but socially invisible, and proposed incorporating this model with biographical disruption model as shown in Figure 2. Stigma and passing concepts were also incorporated in this adaptation, they were introduced by Goffman (1963), implying that a person with a chronic illness can either disclose his/her condition with the risk of being labelled or

stigmatised, or hide the illness and 'passing' it on others (Goffman, 1963). Hence, it is a choice of either taking the risk of being judged by others, or living the subjective experience alone, which could be linked with social support and the biopsychosocial model.

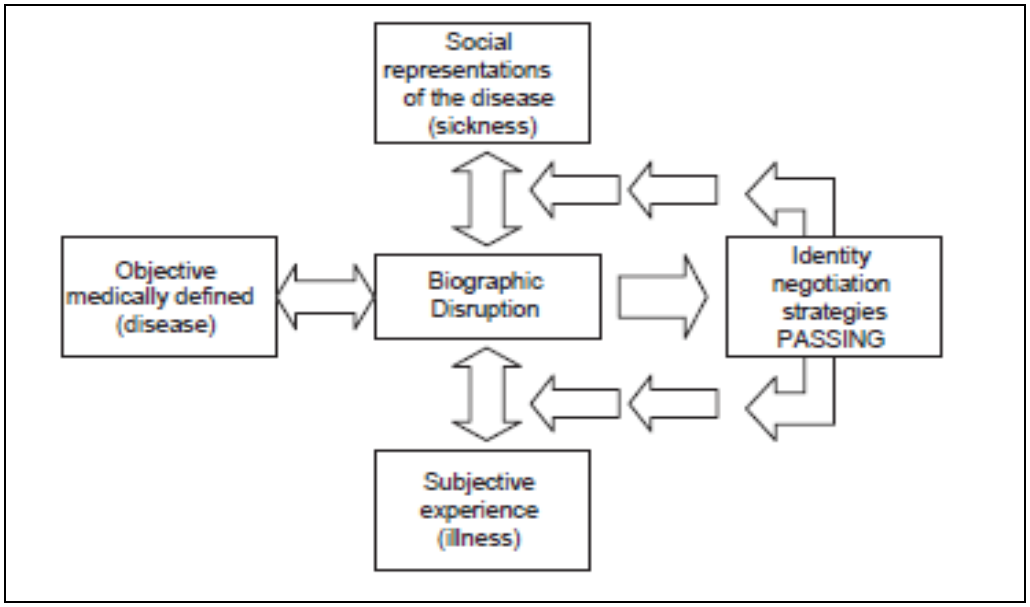

Figure 2. Biographical disruption concept incorporated with diseases-illness-sickness and identity negotiation (Lonardi, 2007)

2.5.3 Conceptualising disability and the biopsychosocial model

Different approaches were adopted to conceptualise disability, mainly the medical and social models. This section discusses the emergence of the social model of disability, its relationship to the medical and the biopsychosocial models, and its relevance to the cyber-victimisation of people with long-term conditions.

Disability discourse was characterised by biomedical dominance, which brought power imbalance, stigmatisation, and discrimination. The medical model of disability focuses on pathology, and its discourse considers body differences as deficiencies or abnormalities that cause functional limitations and require treatment (Barnes and Mercer, 2010). The biomedical model was criticised for the division between body and mind, resulting in a partial concept of

health (Alonso, 2004). The dominance of this model was unparalleled and contributed to the impact upon society and the experiences of people with disabilities. In the 1950s, Parsons (1951) provided a functionalist analysis of social order. In this analysis, Parsons (1951) argued that society relies on healthy, normal, productive individuals. Therefore, an illness in this context was seen as a disruptive event which hinders productivity and society. This disruption was bridged by proposing the 'sick role' as a solution. The sick role is legitimised through medical confirmation of the illness, which entitles the individual a temporary status of illness. Thus, the person will have two responsibilities, first, getting medical confirmation to legitimise the illness, and second, to acknowledge that such illness is undesirable (Barnes and Mercer, 2010). Nonetheless, there were also alleged rights in society following the legitimisation of the sick role (Parsons, 1951). These were a temporary relief from the social role which requires work, and that such sickness is not their fault because it requires management, not simply personal determination. Thus, the sick role brought both labelling and exclusion by individualising the ill person.

The sick role was criticised for being unrealistic (Barnes and Mercer, 2010). First, health could be influenced by diverse elements such as socioeconomic status. Second, it gave the medical profession authority in society. Accordingly, medicine became a tool for transforming lay terms into clinical diagnoses and social roles. Third, it is applicable to acute illness, which brought the question of whether this approach labelled people with chronic conditions as being always impaired and non-functioning individuals. Thus, society constructed disabilities by turning impairment into disabilities (Harpur, 2012). As a consequence, in medical consultations, the authority given to the physicians resulted in power imbalance because the patient needed the input not only for health but also to legitimise the sick role. Despite having medical worries, the patients often disregarded them and claimed to be satisfied with their medical encounters, which reflects power issues (Barnes and Mercer, 2010). In cyber-victimisation cases, the same power imbalance existed, but the disbelief among healthcare

professionals triggered explicit dissatisfaction (Alhaboby et al., 2016). The sick role informed this study by alerting the researcher on avoiding such medical preconceptions and enforcing them on people with long-term conditions. Additionally, the individuals who experienced cyber-victimisation in previous research (Alhaboby, 2017) had similar difficulties in confirming the impact of their experiences medically. Their employment was affected (Maple et al., 2012), yet the impact or the 'Sick role' status was not applicable because the professionals themselves did not understand the situation (al-Khateeb et al., 2017), and because the focus of consultations is probably routine follow-up when it comes to chronic conditions.

Secondary to the social order and the sick role, the sociological discourse started to label people with illness as deviants from norms (Barnes and Mercer, 2010). It was suggested that societal reactions to an illness depend on the degree and visibility of the condition. (Goffman, 2009) suggested that stigma is an implication of these social interactions between 'normal' and 'stigmatised' individuals, which results in dehumanising the person; stigma is described as labelling, and discounting individuals.

Goffman (1990) argued that visible conditions lead to stigmatisation and discrediting individuals. The term discreditable was used to describe people with invisible conditions, because it is up to the individual to decide to whom, and when to disclose the condition. Passing occurs when they decide not to disclose them (Goffman, 2009). In cyber-victimisation cases, the chronic condition itself could be visible or invisible, but then the disclosure of the experience of cyber-victimisation could be passed. For example, mental illness, in this case, causes more stigma, which is relatable to the psycho-social impact of cyber-victimisation (Short et al., 2014). However, stigmatisation looks at people as passive victims, which is not applicable to people with disabilities who are actively involved to promote the welfare of people with disabilities in society, and this was reflected on in section 3.6.2.

In the context discussed above, the social model of disability emerged mainly from the work of Oliver, Sapey and Thomas (2012). The idea came from the Fundamental Principles of Disability document (Union of the Physically Impaired Against Segregation, 1976), it argued that people are not disabled because of their impairments but by societal barriers. This work was the origins of Disability Studies in the UK, where Oliver, Sapey and Thomas (2012) wanted to teach healthcare professional students to inform their practice with this idea; this was followed by the publication of individual and social models of disability. The work mainly targeted people who work closely with individuals with disabilities, in order to re-orient the work to be relevant to the needs of disabled people (Oliver, 2013). The context in which the social model emerged aligns with the aim of this study to examine the experiences of discrimination.

One of the criticisms of the social model is its denial of the impairment which is integral to the lives of people with disabilities (Oliver, 2013). In a paper that explored the contribution of phenomenology to the distinction between disability and impairment (Hughes and Paterson, 1997), an impaired body was considered as an experience, therefore disability is experienced from the perspective of impairment. Accordingly, Sherry (2016) argued, impairment is not a personal apolitical issue, it is shaped by inequality, and there is a need to establish a link between the body, identity, and inequality. This argument is consistent with the original work on the social model which did not suggest abandoning the medical model, nor did it claim that it explains everything that happens to people with disabilities (Oliver, 2013). This aspect is important for this study because its main purpose is to support individuals who go through the experience of cyber-victimisation, in addition to awareness raising to prevent such discrimination. However, the medical aspect is also important for this study because of the impact of the impairment and living with it. Moreover, the social model does consider impairment, so it is a partial explanation of what happens to people with disabilities but focusing on the impairment will de-politicise the issue, and the work was, originally, to improve disabled people's lives. Thus, pain, for example, is an issue for medicine, not politics.

Accordingly, the disability movement can do nothing about pain but can challenge oppression (Hughes and Paterson, 1997)

Challenging the biomedical model resulted in a new conceptualisation of health that incorporates social and psychological aspects of wellbeing (Engel, 1989; Engel, 1960). The resultant psychosocial model was widely adopted in understanding illness (Matarazzo and Leckliter, 1988), public health and health prevention (Huyse et al., 1999) and moves to improve the doctor-patient relationship (Yamada et al., 2000; Mead and Bower, 2000). Formally, the biopsychosocial model was introduced by the WHO following the revision of the International Classification of Functioning, Disability and Health (ICIDH-2) (World Health Organization, 2001). It is claimed that it is a synthesis of both the medical and social models (Barnes and Mercer, 2010). However, two major issues challenged the implementation of this model in practice. First, doctors were more resistant to this model, with little and slow adoption compared to other disciplines (Alonso, 2004), so this is also related to the support available to people with chronic conditions who experience victimisation. Second, the biopsychosocial model transferred some of the responsibility to the patients. This is an additional issue that adds to the stigmatisation and the role of social support.

Oliver (2013) argued that, after the global economic challenges in 2008, focusing on the impairment was a strategy that did not protect disabled people. Instead, the criticism of the social model was used to bring the impairment and differences back and ignore the disabling barriers. This is consistent with Harpur's (2012) discussion on the need to shift the focus onto abilities rather than disabilities, because the word disabled is increasingly serving the ablest ideology, by enforcing exclusion and oppression. This aligns with Oliver's (2013) notion and explains justifying benefit cuts by prioritising those who are in more need and described as severely impaired. Additionally, medicalisation is another issue that played a role in depoliticising and individualising problems which result in victim blaming and further discrimination. The medicalisation of everyday life is a gradual process in which an everyday

life problem is perceived as bad, or weak, requiring treatment and hence given a medical diagnosis (Barnes and Mercer, 2010). For example, a study in Taiwan reflected, from the perspective of 24 disabled people, how despite the adoption of the International Classification of Functioning, Disability and Health, disability was still medicalised and led to unfair assessment and benefit cuts (Chou and Kröger, 2017). This supports Oliver's (2013) argument that differences were used to affect services rather than removing barriers, and disabled people were forced back into the role of tragic victims. Medicalisation also overlaps with looking good (Barnes and Mercer, 2010), which could be one of the contributing factors to the cyber-victimisation of people with disabilities.

The role of professionals is controversial when it comes to adopting the social model of disability. The social model developed over time, garnered support, and helped in developing collective disability consciousness. The early critics were mainly from disability charities and professional organisations, due to the impact of this model on their authority at that time (Oliver, 2013). Later on, these organisations adopted the model and advocated for it, and this also applies to healthcare professionals and researchers. However, the risk arises from the argument that non-disabled experts in the field caused harmful influence and abused this model (Barnes and Mercer, 2010). Moreover, recognising that people with impairments are experts in their own bodily experiences led to adopting phenomenological theories and research to address both corporeal and social experiences (Sherry, 2016). However, this was undermined due to framing the participants' accounts through the lens of individualism and medicalisation which led to overlooking the social factors surrounding the bodily experience (Sherry, 2016). This study does not address the embodiment of participants' experiences, however, this was an alert to ensure recognition of the social factors, the role of professionals in framing the issues, and the fidelity of this research in improving the experiences of people with disabilities.

Interpretive accounts were employed to help people make sense of their experiences (Barnes and Mercer, 2010). Such an approach acknowledges the relationship between chronic conditions, the availability of resources, and the context of the accounts, which influence social and psychological issues. This approach is similar to the researcher's stance and a phenomenologically informed approach (section 3.2.1). This is where the concept of biographical disruption (Bury, 1982) was introduced, a sociomedical approach combining medical knowledge, human interactions and interpretations of the lived experience in terms of physical, social and psychological impact. Biographical disruption discussed the preoccupation with managing the chronic illness to keep up with others (Bury, 1982). However, Williams (2000) challenged the model and suggested that it exaggerates the degree of change. Section 2.5.1 addresses further arguments on the biographical disruption concept.

One of the consequences of considering the diagnosis of a chronic illness as a disruptive event is the mobilisation of psychosocial resources (Bury, 1982). Social support is one of the primary recognised aspects of the psychosocial element in health (Revenson et al., 1991). It is a resource that could buffer the effect of stress and prevent health deterioration. The model of social support was adopted to explain cyber-victimisation of people with chronic conditions. This was through the main effect model which considers that support is always helpful, and the stress-buffering model, which considers that support depends on the level of incident or stress caused (Fridh, Lindström and Rosvall, 2015). It was found that social support is a buffer to the impact of cyber-victimisation.

People with chronic conditions benefit from social support due to the long-term course of the illness, that is often is associated with depression or helplessness (Alonso, 2004). However, the utilisation of social support as a resource is challenging, because not all social interactions with people with chronic conditions are considered helpful, even those with family or friends, known also as informal support channels. This was examined in a group of 101 newly diagnosed cases of rheumatoid arthritis (Alonso, 2004). It was found that positive social

interactions resulted in less depressive symptoms compared with problematic social interactions that resulted in depressive symptoms. It was found that the incidence of depression was highest among people with chronic conditions, and subjected to both problematic interactions and little support. This could be related to cyber-victimisation because harassment could be the result of non-beneficial social interactions.

2.5.4 The self-management of chronic conditions and biographical disruption

Self-management is the active engagement in managing an illness, hence it is a dynamic process. It is the ability of the individual collectively with his/her family, community and healthcare professional to manage the chronic condition in terms of symptoms, treatment, lifestyle changes and psychosocial support (Richard and Shea, 2011). Hence, it is different from self-care, which implies a more generic and physical care.

In a qualitative review of 101 studies, three themes of the self-management process emerged (Schulman-Green et al., 2012). The first theme was ‘focusing on the illness’, which included activities and skills development in learning about the conditions, taking ownership of health needs and health promotion. The second theme ‘activating resources’ presented four types of resources: the relationship with healthcare providers, psychological, social, spiritual and community resources. The third theme ‘living with chronic illness’ included elements of processing emotions, adjusting to both illness and new self, integrating illness to daily life and meaning-making. The implications identified by the researchers were the need to acknowledge these different elements of self-management by healthcare professionals to facilitate self-management.

There is no direct connection between the terminology and self-management. However, researchers argue that self-management is rooted in the biographical disruption model (Morden, Jinks and Ong, 2015), specifically how Bury (1982) described the meaning of living

with the illness and the meaning of bodily consequences of having a chronic condition. Both self-management and biographical disruption were used to conceptualise research on chronic conditions, this went beyond looking at specific conditions to specific symptoms too. For example, looking at knee pain resulting from osteoarthritis as a potentially disruptive event due to the meaning it has to people, such as the risk of developing an impairment. Such meanings can influence actions needed for self-management (Morden, Jinks and Ong, 2015).

Self-management shares with the biographical disruption model the concept of mobilising psychological resources (Greenhalgh, 2009), which indicates that it is a second stage after disruption and could be directly affected by repeated disruptions, raising the question whether another stressful event, such as cyber-victimisation, is experienced as a separate disruption or a continuous disruptive event in the chronic disease cycle.

2.5.5 Cyber-victimisation and biographical disruption

There is limited theory on the impact of cyber-victimisation (Short et al., 2014) and on its relation to chronic conditions (section 2.4). This section highlights the similarities between chronic conditions and cyber-victimisation, raising the question about applying biographical disruption model to both. Biographical disruption is based on the fact that the diagnosis of a chronic condition is a major event in life, and it was found that cyber-victims perceive this experience as a major event that changed them forever (Maple, Short and Brown, 2011; Alexy et al., 2005; Dreßing et al., 2014; Short et al., 2014). Furthermore, it was found that the diagnosis of chronic disease is sometimes associated with PTSD (Alonzo, 2000). This reflects the disruptive nature of living with this illness. This also supports the argument whether the concept of biographical disruption applies to cyber-victimisation, which is also significantly associated with PTSD (Dreßing et al., 2014; Maple, Short and Brown, 2011).

Cyber-victimisation impacts on psychological wellbeing and disrupts social relationships which are part of the psychological resources (Dreßing et al., 2014). This is a core issue in chronic diseases self-management (Greenhalgh, 2009) and one of the main building blocks covered in the biographical disruption model (Bury, 1982). Hence, mobilising psychological resources is a common factor between cyber-victimisation, The self-management of chronic conditions and coping with disruptive events in life.

Moreover, if the diagnosis of chronic illness changes the status of 'taken for granted' related to health issues, the person has to live with the new diagnosis and the complications of chronic illness unlike before (Bury, 1982). This might apply to cyber-victimisation as victims showed 'trust' in online relationships and taking them for granted (Galeazzi et al., 2009), while after the experience of cyber-victimisation they become extremely cautious, isolated and afraid (Dreßing et al., 2014; Short et al., 2014). This is complicated by not taking the victims of cyber-victimisation seriously and even blaming them, which could be due to underestimating online dangers (Kamphuis et al., 2005). This could resemble the notion of the difficulty of legitimising an illness with very prevalent symptoms (Bury, 1982). Accordingly, if the pain is common and not legitimised, then the use of electronic devices is common and its harms are underestimated. Moreover, some conditions could be medically categorised, but not socio-culturally legitimised as discussed earlier.

Consequently, it could be assumed that cyber-victimisation 'behaves' like a chronic illness in disrupting victims' lives. Thus, research is needed to address this issue and explore whether it is true or not, and whether cyber-victimisation acts as a chronic illness by itself or it interacts with the pre-existing chronic condition to result in a series of disruptive events, and how could this be further addressed by professionals. Based on the discussion above in sections 2.4.1 to 2.4.5, Figure 3 was developed to illustrate the conceptual framework underpinning this study.

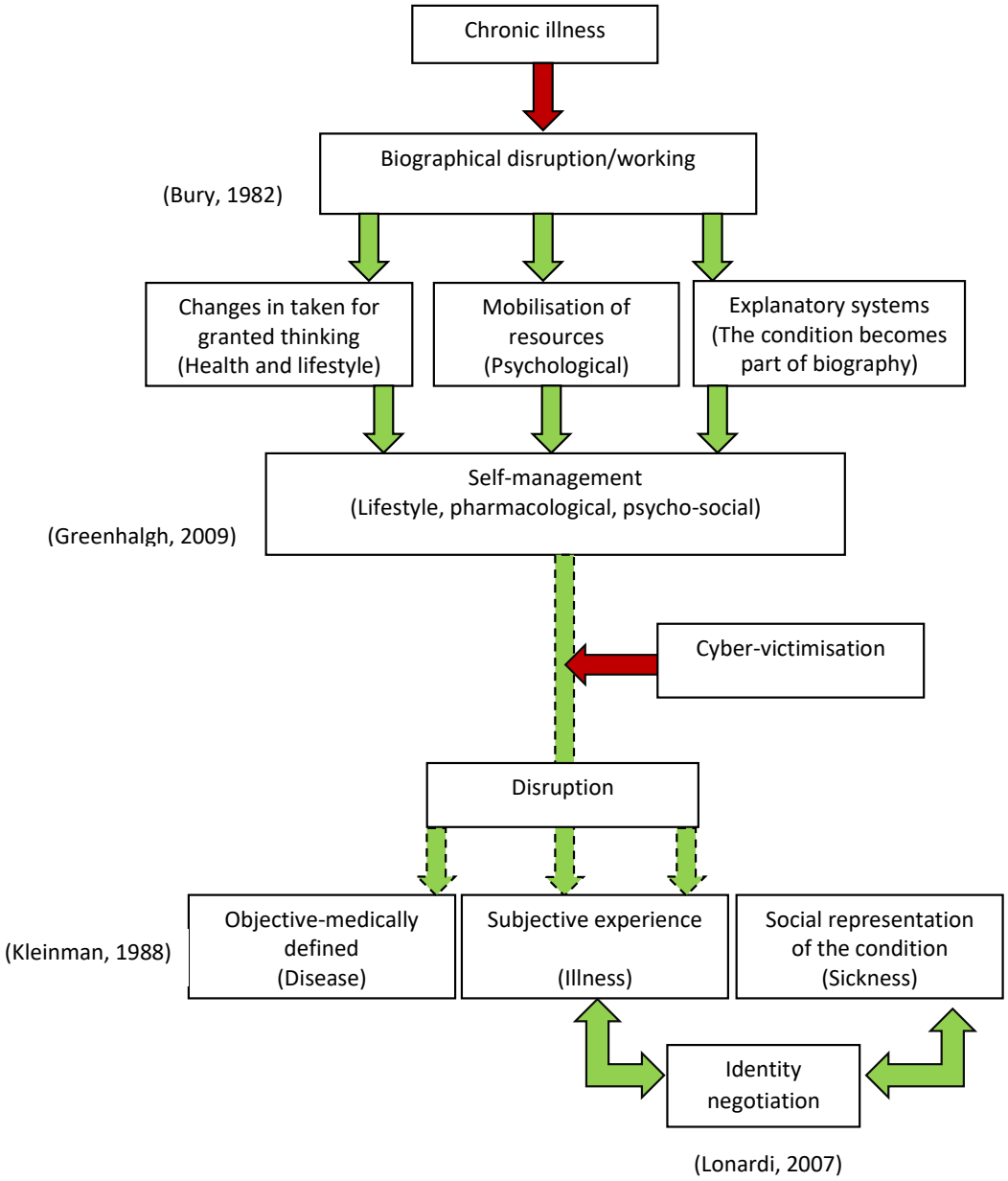

***Figure 3**. The theoretical framework underpinning this study*

The framework proposes that developing/having a chronic condition is a disruptive event. It changes the thinking of self, as well as changing the thinking-for-granted. It also requires mobilising psychological resources. Once this happens, life will change, but the self-management that is rooted in this disruption starts to control or help in coping with the situation. However, when being a target of cyber-victimisation, a second disruption could happen. This

time, the disruption happens on the existing condition and it could have a different impact on the disease, illness or sickness. This impact could also vary based on identity negotiation by the patient/victim that is influenced by psychosocial factors.

2.6 Summary

In this chapter, the supportive background for this study was discussed to understand chronic conditions, self-management, cyber-victimisation, the impact upon victims and support. This was further interrogated through conducting a systematic review that revealed the gaps in the literature such as the context, sample, and conditions covered. The theoretical underpinning this study was developed using the biographical disruption model, social support and disease model. This background from literature and the theoretical framework had influenced the methodology and methods adopted in this study, as will be discussed in chapter 3.

Chapter 3

Methodology

3.1 Introduction

A mixed-method design was adopted in this research. Both quantitative and qualitative approaches are well established in the literature, but a long-term debate on the dominant methodology also exists (Onwuegbuzie and Leech, 2005). Quantitative research is used in healthcare to synthesise evidence, while qualitative research provides an in-depth understanding of the evidence that could not be fully addressed by quantitative methods (Andrew and Halcomb, 2009; Ivankova, Creswell and Stick, 2006). In the UK, health researchers (Greenhalgh, Howick and Maskrey, 2014) are calling for strengthening of the qualitative research element to reach a holistic approach. These attempts were successful in reshaping how the WHO addresses qualitative methods in evidence based medicine (Greenhalgh, 2016). Hence, both approaches, quantitative and qualitative, are acknowledged and a mixed-method design provides a relative middle ground between this traditional dichotomy (Seale, 2012). This chapter explains the overall study design and its philosophical underpinning, followed by a detailed discussion of the methodology and methods used, such as instruments, piloting, sampling, data collection, analysis and ethical considerations. In this chapter, the methodology is defined as the general approach adopted by the researcher to guide the study, think about the research question, and influence the justification of using certain methods, while the methods are the specific tools to be used by the researcher for data collection and analysis (Giddings and Grant, 2007)

3.2 Study design

Mixing methods existed for more than 65 years, it is a systematic approach that is being increasingly used to answer research questions by employing both quantitative and qualitative

data (Andrew and Halcomb, 2009). It was adopted in this study due to several reasons. This section discusses the philosophical influence of phenomenology on this study's design (Section 3.2.1), a discussion on the justification of mixing methods (section 3.2.3) and the overall design.

3.2.1 Philosophical influence on the research design

Epistemological philosophy looks at the nature and scope of people's experiences (Gray, 2014); it aligns with the philosophical stance of the researcher to understand the impact of cyber-victimisation from the perspective of people who experienced it. Furthermore, an inductive approach helps to cover this unexplored area to look for emerging relations or themes and this applies to cyber-victimisation (Reyns, Henson and Fisher, 2012; Kowalski and Fedina, 2011). This section discusses the philosophical influence on the design of this study.

Pragmatism is the philosophical stance that often underpins mixed-method research (Andrew and Halcomb, 2009; Johnson and Onwuegbuzie, 2004), however, it does not align with this study's aim which focuses on the first-hand experience of the participants. Pragmatism is a logical way of thinking; it views truth based on its practical consequences and embraces multiple viewpoints of the research problem (Johnson and Onwuegbuzie, 2004). In the case of cyber-victimisation, the experience is still under-explored (Short et al., 2014; Alhaboby et al., 2017b) and victims often claim that they are neither being understood nor believed (Fazio and Galeazzi, 2004; Galeazzi et al., 2009; Reyns and Englebrecht, 2014) (Appendix 24). Thus, a phenomenological approach is more appropriate because it is accountable to the human experience (Giorgi, 2009; Gerrish and Lathlean, 2015). Therefore, a constructive phenomenology-informed approach was adopted as illustrated in Figure 4.

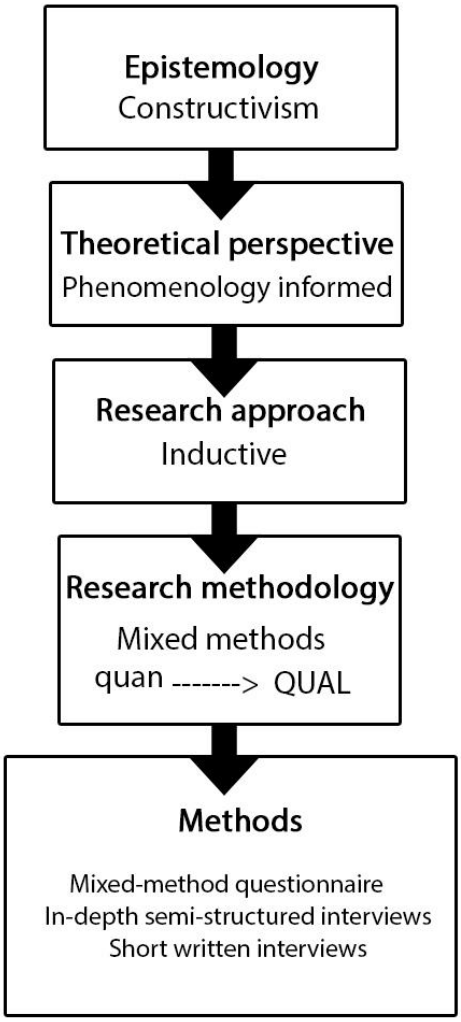

Figure 4. Philosophical influence on research design, methodology and methods, adopted from (Gray, 2014; Crotty, 1998)

Phenomenology is a term that involves different meanings; it mainly implies the experience of the world as we immediately live it without conceptualisation (Given, 2012). Accordingly, it may explore the unique meanings of any human experience in the world, such as experiencing illness (Given, 2012). Phenomenological enquiry became increasingly popular (van Manen, 1990); it came from philosophy and psychology where the researcher describes the lived experience of the phenomenon (Creswell and Creswell, 2018). In a phenomenological enquiry, the world is experienced, subjective, in our minds. It places

people's experiences as a starting point for investigations and making meaning (Seale, 2012). In this study, the main aim was to understand the impact of cyber-victimisation on people with long-term conditions from the perspective of people who experienced it. Thus, this research is phenomenology-informed, to explore this phenomenon as a first-hand experience. This research was influenced by the main essence of phenomenology, which is a style of thinking, and a manner of orienting the experience as we live through it (Given, 2012).

Phenomenology emerged from Edmund Husserl's work in the 1970s (Husserl, 1970), as a novel way of studying the phenomenon of conscious experience (Giorgi, 2012; Harré, 2006). This was followed by the development of several phenomenological models. Transcendental phenomenology involves the work of Edmund Husserl and his interpreters, who describe the essence of meaning through consciousness. Moustakas (1994) adopted the descriptive approach, which involved examining the entity from many perspectives until the essence of the phenomenon is revealed, and is committed to the description of the experience, not the analysis or explanation (Moustakas, 1994). Strictly descriptive phenomenological methods were also adopted in the work of other researchers (Giorgi, 2009; Giorgi, 2012; Giorgi, 1970) who looked at psychology as a human experience. This is the most relevant phenomenological stance to this study, which provides a descriptive account in order to understand the experience of cyber-victimisation from the consciousness of people who went through it.

Other phenomenological approaches that were less relevant to this study include existential, hermeneutic, ethical and linguistic phenomenology. Existential phenomenology focuses on how the being of beings shows itself as revealing of being itself. The work by Heidegger (1962) is a prominent example of this approach. It is different from ethical phenomenology, which looks at otherness, responsibility, and what is other than being (Given, 2012). Further, hermeneutic phenomenology (van Manen, 1990), is interpretative rather than descriptive. It involves interpretation, textual meaning and dialogue. However, Heidegger

(1962) argued that all human description is already an interpretation and every form of human understanding is interpretive. Other phenomenological approaches gave special consideration to language. For example linguistic phenomenology, which is relevant to the work by Michel Foucault on the nature of language and discourse (Dreyfus and Rabinow, 2014) even though Foucault did not consider himself as a phenomenologist (Given, 2012).

In practice, phenomenological approaches are increasingly adopted, particularly in health sciences, education, psychology, pedagogical disciplines (Given, 2012). This encouraged adopting this approach for this study because its multi-disciplinary nature involves the impact of cyber-victimisation on physical and mental wellbeing, the encounters with professionals and awareness raising through health promotion.

In research, the phenomenological approach is mainly to explore the subjective nature of the phenomenon rather than generalisation (Seale, 2012). Thus, in the analysis, the main focus is contextualising qualitative data (Teddlie and Tashakkori, 2009), and examining what is unique and what is shared in experiencing the phenomenon under study (Butler-Kisber, 2017). It is also acknowledged that a good phenomenological research text can make us see something in a manner that enriches our understanding of everyday experience (Given, 2012). This is another aspect that aligns with this study because it helps to reflect the cyber-victimisation experience, and communicates to the wider audience. Accordingly, data-gathering activities, such as interviews, observation, written descriptions, or remembered stories, can be empirical (Given, 2012). This is important for this study due to the scarcity of a qualitative element in cyber-victimisation research, specifically with people having long-term conditions (Alhaboby et al., 2017b). Thus, the qualitative element was prioritised in this study and the justification for adopting a mixed-method design, as will be discussed in section 3.2.3.

Mixing methods is a documented practice in phenomenological research inquiry as will be discussed in relation to sampling (section 3.3.3). A phenomenological study in Australia

focused on how young people with disabilities experienced bullying in schools and the informal support they received from friends and family (Bourke and Burgman, 2010). Emergent themes included bullying experiences, coping with bullying, the importance of friends, and adult responses to bullying (Bourke and Burgman, 2010). These themes were similar to the documented cyber-victimisation experiences (Sheridan and Grant, 2007). The researchers reported the work as a phenomenological study (Bourke and Burgman, 2010), they recruited 10 participants with variable characteristics and different long-term conditions. Multiple in-depth interviews were carried out and transcribed verbatim. The interview transcripts were analysed thematically. Short et al. (2014) also used thematic approaches to examine the lived-experience of cyberstalking victims. The research conducted by Bourke and Burgman (2010) informed healthcare and educational professionals to understand the experience of victimisation and mitigate it. The above approach supports this study because it shares a similar philosophical stance, target population, and impact aimed at in my research.

3.2.2 Overall design

The overall design is summarised in Figure 5 and further broken down in Table 1.

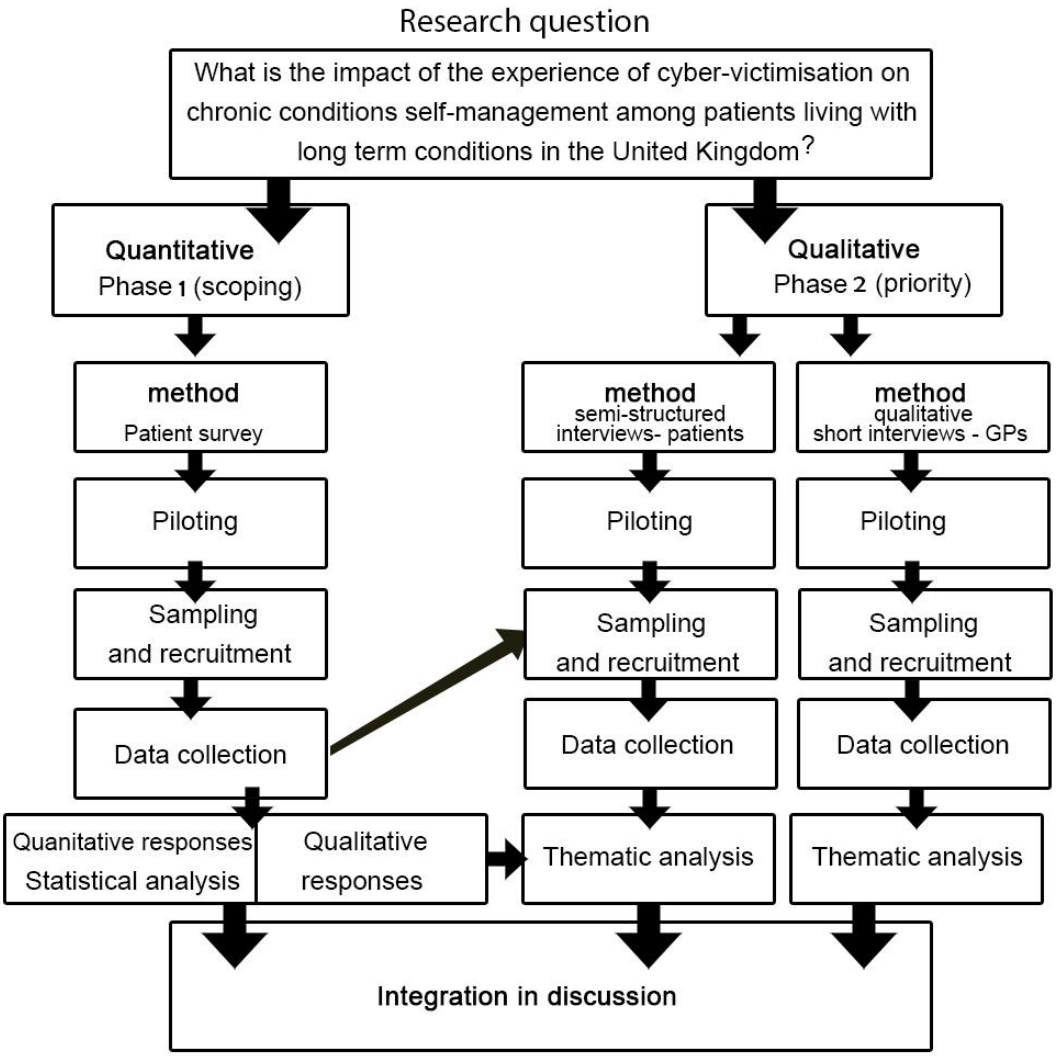

Figure 5. *Summary of the study design explaining its phases and the points of interface*

The systematic review provided a supportive background to this study (section 2.4). The first primary data collection step was from people living with chronic conditions in a cross-sectional study to examine the extent of cyber-victimisation among people with long-term conditions. The outcomes of this stage were quantitative to scope the prevalence and impact, qualitative results and identification of a sub-population to recruit participants for the next phase. This phase is described in detail in section 3.3.

The second phase addressed the experiences of cyber-victimisation from the perspective of victims themselves with chronic conditions (section 3.3.1). This helped in building an understanding of the experience from the views of people who went through it, hence this objective will provide the main building block for the health promotion tool (Seale, 2012; Silverman, 2013). This was concurrently strengthened by the understanding and experiences of the perspective of GPs (section 3.4.3) because of their role in supporting victims/patients (Fazio and Galeazzi, 2004; Kamphuis et al., 2005). Two sets of themes were anticipated, from the victims and GPs. These themes were integrated and triangulated with the questionnaire results in the discussion in chapter 6.

The findings from both phases were used to develop a health promotion tool to increase the awareness of this phenomenon. The health promotion information was shared with the victims and gatekeepers for their input to shape it as co-researchers and improve it.

3.2.2.1 Priority and integration

Priority is the relative weight assigned to the quantitative and qualitative research components of a mixed-method design, it can be given to either of them regardless of the design being concurrent or sequential (Kroll, Neri and Miller, 2005; Andrew and Halcomb, 2009). In this research, the priority was given to the qualitative element due to the scarcity of qualitative research in the area of cyber-victimisation (Short et al., 2014; Mishna, McLuckie and Saini, 2009) and the phenomenological influence to address these experiences in-depth (Mayoh and Onwuegbuzie, 2013).

Integration, or the point of interface, implies the point where mixing of quantitative and qualitative methods occurs (Creswell et al., 2011). It can be at the study design level, methods level, analysis, or at the level of interpretation (Siddiqui and Fitzgerald, 2014; Fetters, Curry and Creswell, 2013). In this study, integration was considered at the level of the research

design because the quantitative phase has informed qualitative phase sampling (section 3.4.1.1). Findings were integrated in the discussion (Chapter 5) to explain and strengthen each other.

Table 1. Breakdown of the methodology and methods used to meet each objective in this study on the impact of cyberstalking on the self-management of chronic conditions

Objective	Methodology	Method	Sample	Analysis	Input
Objective 1	Quantitative and qualitative	Participant survey	Random sample and snowballing	Descriptive data and cross tabulations + Thematic analysis	Scoping the experience of cyber-victimisation and health issues in people with chronic conditions, and looking for possible victims' characteristics. Identifying participants for the qualitative phase. ***Input to health promotion:*** Providing figures on the phenomenon to illustrate the scope and facilitate communication with stakeholders.
Objective 2	Qualitative	In-depth semi-structured interviews with patients/victims	Purposeful sample	Thematic analysis	-In-depth understanding of victims' experiences ***Input to health promotion:*** Findings provided the main building block of the health promotion tool to increase

					awareness on cyber-victimisation impact and reshape support provided.
Objective 3	Qualitative	Short written interviews - GPs	Purposeful sample	Thematic analysis	Understanding healthcare professionals' perspectives in relation to their experiences with chronically ill patients and general medical knowledge. ***Input to health promotion:*** Strengthening health promotion by incorporating input from medical experience and knowledge.

3.2.3 Mixed-method design

Mixed-method design is considered by many researchers to be a peaceful middle ground in the long-term paradigm debate on adopting quantitative or qualitative research methods (Teddlie and Tashakkori, 2009). In the literature, there are various justifications used by researchers to adopt mixed-method research (Bryman, 2008).

In order to examine researchers' justifications for adopting a mixed-method design, Bryman (2008) conducted a project that involved a content analysis of 232 mixed-method articles, and interviews with researchers who used this approach. The analysis adopted a unified scheme to examine two aspects of the included articles: first, the rationale reported by the authors, and second, how this was actually applied in research. The enquiry included 16 categories of justifications for adopting a mixed-method design: *triangulation, offset, completeness, process, different research questions, explanation, unexpected results, instrument development, sampling, credibility, context, illustration, utility, confirm and discover, diversity of views and enhancement*. Most of these justifications were applicable to rationalise adopting mixed-method design in this study, and they will be briefly discussed below in relation to justifying this research design.

Triangulation, or greater validity, is using more than one method to cross-check results addressing one issue (Seale, 2012; Bowling, 2009; Mayoh and Onwuegbuzie, 2013). Triangulation differs from multiple-methods which implies using different methods to address different aspects of the research question to form an answer (Seale, 2012; Bowling, 2009). Triangulation is used to increase confidence in recommendations and minimise bias (Seale, 2012; Bowling, 2009; Mayoh and Onwuegbuzie, 2013). In the articles analysed by Bryman (2008), researchers in 19 articles used triangulation as a rationale, and with the progression of the research, 80 articles were implementing triangulation during the research process. In this study,

triangulation was part of the rationale to adopt mixed methods and was implemented by cross-checking the findings of each stage of the study to enhance validity and respond to the research question.

Offset is another justification which refers to the suggestion that quantitative and qualitative methods have their own weaknesses and strengths, so their combination helps to overcome weaknesses and strengthen each other (Seale, Rivas and Kelly, 2013; Johnson and Onwuegbuzie, 2004). The strengths of a quantitative approach include testing theories and the validity of the results in the sample population or externally on other populations; it is less time consuming and the results are potentially generalisable (Johnson and Onwuegbuzie, 2004). The quantitative approach helps in the general mapping of the extent of the issue under study (Mayoh and Onwuegbuzie, 2014). In this case, it is known that cyber-victimisation is related to adverse health effects and has variable prevalence (Dreßing et al., 2014; Short et al., 2014). However, there is no consistent figure on cyber-victimisation prevalence among people living with long-term conditions in the UK. Therefore, situating the issue was used as a first step, but quantitative methodology does not reflect experiences, understandings or explaining the phenomenon in reality (Andrew and Halcomb, 2009). To overcome this, the qualitative methodology provides an in-depth understanding of the issue under study, and its inductive nature helps to generate knowledge during the research process which is beneficial in studying new or unexplored areas (Seale, 2012; Greenhalgh and Wengraf, 2008). Nevertheless, qualitative methods could be time-consuming and not generalisable (Bowling, 2009; Silverman, 2013). Accordingly, both methodologies were needed in this study by first scoping the experience of cyber-victimisation among people living with chronic conditions and then further exploring its impact. Thus, offset as a justification was helpful in this research because the survey provided a scope of the issue, but needed in-depth understanding which was supported by the interviews.

Completeness is also a rationale for mixing methods. This design is considered advantageous in its flexibility of design and the comprehensiveness of data collected (Johnson and Onwuegbuzie, 2004). Therefore, a mixed-method design is used when there is insufficient information in the literature and requires multiple methods to answer those information needs (Andrew and Halcomb, 2009). This justification was also applicable in this study due to the gaps in knowledge on the impact of cyber-victimisation on people with chronic conditions (Reyns, Henson and Fisher, 2012) which is demonstrated in detail in Chapter 2.

Process as a justification means that quantitative methods provide an account of structures of social life, however, qualitative methods help in making sense of the process (Seale, 2012). This justification aligns with this research due to the relatively recent emergence of cyber-victimisation as a problem (Alhaboby et al., 2016) and the need to make sense of it based on the experiences of people who went through it. This also aligns with examining the experience from a phenomenological perspective (Butler-Kisber, 2017).

Explanation is documented in the literature as a reason to combine methods, in which the resultant data from quantitative and qualitative methods explain each other (Bryman, 2008). This was planned at early stages at the research and further confirmed at the analysis stage. To achieve this, the sequence of mixed methods was considered at the planning stage. Sequential mixed-method design aligns with phenomenological mixed-method research (Mayoh and Onwuegbuzie, 2014). It represents a 'phases-approach' where findings from one type of data, for example a survey, are followed by another type of data collection, such as interviews (Andrew and Halcomb, 2009). This is different from concurrent mixed-method design which involves carrying out quantitative and qualitative data synthesis at the same time (Andrew and Halcomb, 2009). Sequential mixed-method design can be exploratory when the qualitative phase precedes the quantitative one, transformative if it is informed by theory, or explanatory when the quantitative

phase is followed by a qualitative phase to explain findings (Neri and Kroll, 2003). An example of how this was further applied in this study is the statistically significant relationship between disability and cyber-victimisation, which was further explained by the sixth theme in qualitative data (section 4.3).

Unexpected results are also a justification to mix methods; this happens when the quantitative or qualitative methods result in a surprising finding that is further investigated employing the other methods (Bryman, 2008). This was not part of the initial planning in this study. However, upon analysis, the first theme implied that physical impact occurred after a long duration of victimisation. This finding was taken to re-visit the survey, and surprisingly, when the duration was categorised in two variables, the results were statistically significant (section 4.2.6.3).

Instrument development refers to using the qualitative input to develop tools such as the questionnaire and impact statements (section 3.3.2). This was important for the re-phrasing of questions in the interview guide based on the input from the survey, and adding a question to the GPs based on the input from the participants (Appendix 19). This justification also aligns with the phenomenological-informed stance, because when the research tools, such as the questionnaire (Appendix 11) or the interview guide (Appendix 12) are constructive, a phenomenological approach is more suitable (Mayoh and Onwuegbuzie, 2013).

Sampling as a rationale implies the situation where one approach informs the sampling of the other approach. This was one of the main reasons to mix methods in this study because the issue of cyber-victimisation required scoping first to define a sub-population for the interviews. Employing such an approach in the phenomenological mixed-method design was documented; orientation and scoping using quantitative methods was followed by identifying a sub-population

for the qualitative phase (Mayoh and Onwuegbuzie, 2014), which confirmed adopting a sequential mixed-method design in this study.

Mixing methods is also important to ensure the quality of work. This is documented in two ways. First, *credibility*; it is suggested that mixing methods enhances the credibility of the findings. This was one of the supportive arguments to employ mixed methods in this study and to further examine the quality of this research as will be discussed (section 5.11). Second, *enhancement*, which means that qualitative and quantitative findings augment each other. This rationale constituted the approach adopted in almost one-third of the articles analysed by Bryman (2008), and it is consistent with the discussion on cross-checking the findings in this study and its validity.

Context refers to contextualising quantitative data using the qualitative one approach to generate valid or uncovered findings (Bryman, 2008). This was helpful in this study to uncover relationships between variables with an explanation such as the self-reported disability, duration, and the overall description of cyber-victimisation phenomenon in theme 3. It is also relevant to the phenomenological enquiry because one of its challenges is the question of context; each context results in different experience and possibly different phenomenon (Butler-Kisber, 2017), and addressing this needed mixing methods.

There are other justifications to suggest mixed methods were relevant to the health promotion aspect of this study. First, *illustration*, which is employing qualitative data to illustrate quantitative data. This was part of the initial plan of this study and was further used in the health promotion design (section 4.5.2). Second, *utility*, which implies improving the usefulness of data especially when the target audience are professionals (Bryman, 2008). Professionals were considered as a potential audience for this study's findings due to the struggle of the people who experience cyber-victimisation to get support (Alhaboby et al., 2016).

The *diversity of views* is another relevant rationale for this study, by combining different perspectives such as practitioners and participants (Bryman, 2008). This aspect supported the justification of mixing methods in this study, because in the literature there was a lack of qualitative research, and people experienced denial of support from practitioners (Galeazzi et al., 2009; Reyns and Englebrecht, 2014). Moreover, public health research informs policy and interventions to improve population health. However, generating this evidence is poorly informed by people with disabilities (Berghs et al., 2017), hence it was necessary to get input from the participants' and GPs' perspectives as a supportive channel (section 2.3.4.1).

Some justifications for mixed methods were less relevant to this study. First, *different research questions*; in this argument researchers combine methods to respond to different research questions (Bryman, 2008). This justification was not applicable to this study because the research had one research question. However, the research question had different aspects that required multiple methods to answer. Second, *confirm and discover*; some researchers mix methods to generate a hypothesis. However, this was not planned in this study because of its inductive nature and the priority was given to the qualitative component (section 3.2.2.1).

Further to the justifications discussed above, Creswell and Creswell (2018) identified six potential reasons to combine methods. Four of them were consistent with Bryman's (2008) analysis, these were: comparing different perspectives, explaining quantitative findings, developing better measuring instruments, and understanding participants' views. Additionally, the last two justifications by Creswell and Creswell (2018) were important to support mixing methods in this study; these were: developing an understanding of needed changes to call for action to help marginalised groups, and understanding the need for an impact of an intervention. This justification fits this study, that people who experience cyber-victimisation are marginalised and misunderstood (Short et al., 2014), and because the aim was to employ findings to initiate change.

In addition to the content analysis above, Bryman (2008) conducted interviews with 20 researchers who employed mixed-method design and identified two main themes. The first theme aligns with the sixteen rationales above, such as providing an explanation, meaning, or the development of tools. The second theme was on the expectations of stakeholders such as funding bodies or journal editors. It was perceived by the interviewee that mixed-method research had more acceptability (Bryman, 2008). This was also a rationale for undertaking mixed methods in this study, due to the nature of the topic and people with long-term conditions who experienced victimisation being marginalised. In order to improve the support available to victims, communicating findings to support channels is necessary (Fazio and Galeazzi, 2004; Galeazzi et al., 2009; Kamphuis et al., 2005; Reyns and Englebrecht, 2014). This was an essential aspect supporting mixing methods in this study where the aim was to use the findings for health promotion, hence the use of mixed methods served to address this issue because stakeholders tend to understand the magnitude and nature of the problem being presented in quantitative and qualitative data respectively (Andrew and Halcomb, 2009; Creswell et al., 2011).

The weakness of mixed-method design lies in its requirement for time and resources, and that the researcher is expected to have knowledge of both quantitative and qualitative methods (Teddlie and Tashakkori, 2009). Thus, it is usually conducted by a team and could be a challenge when adopted by a single researcher (Johnson and Onwuegbuzie, 2004; Silverman, 2013; Bowling, 2009).

3.3 Phase one: Online survey

3.3.1 Target population

This phase targeted individuals living with chronic conditions and disabilities in the UK to examine their cyber-victimisation experiences. The section below describes the scope of defining chronic conditions, cyber-victimisation, the age of the target population and the justification behind the inclusion criteria in this study.

3.3.1.1 Defining a chronic condition and self-management

A chronic condition was identified in this research by self-reporting of the diagnosis (Davis, Coker and Sanderson, 2002). The criteria to identify cases were: a) having a long-term health condition with a duration of more than 3 months, which is the duration agreed on medical diagnosis as discussed above, and b) the condition is likely to last for more than 12 months according to the Equality Act definition (Equality Act 2010). An additional criterion that differentiates this study is the inclusion of self-management in case identification, which includes lifestyle changes, follow up and/or medications (Bodenheimer et al., 2002; Kralik et al., 2004; Norris, Engelgau and Narayan, 2001; Sattoe et al., 2015). This was to respond to this study's aim in examining the impact of cyber-victimisation on the self-management of chronic conditions. Hence, participants were identified as having a chronic condition if they responded 'yes' to this question *'Do you have a long-standing medical condition/illness or disability that requires monitoring, lifestyle changes and/or taking medications? By long-standing, we mean anything that has affected you over a period of at least 3 months or that is likely to affect you over a period of at least 12 months'.*

3.3.1.2 Defining cyber-victimisation

Cyber-victimisation in this research was defined based on self-reporting of the qualifying criteria below, this was further supported by the self-reported 'victim status'. Employing two ways to identify victims and cross-check the results helped in linking previous approaches by researchers which either used self-reporting (Maple, Short and Brown, 2011) or looked at specific criteria (Dreßing et al., 2014). The definition adopted considered the discussion on the inconsistency in defining cyber-victimisation cases (section 2.3.2.2), and the criteria adopted by most researchers, mainly being an unwanted communication, repeated, via electronic means (section2.3.2). Fear was not used as a qualifying criterion because it was considered as an additional factor and linked to the theoretical framework (section 2.5). There are inconsistencies in the literature in setting a threshold for the duration of cyber-victimisation (Dreßing et al., 2014; Galeazzi et al., 2009; Purcell, Pathe and Mullen, 2004). In UK legislation, the Malicious Communications Act 1988 and the Communication Act 2003 suggested the need for a high threshold for online communication offences, but did not provide an exact duration (Malicious Communications Act 1988). Hence, in this study, the victims were asked about the duration to report it as a finding.

3.3.1.3 Participants targeted demographics

Participants from all genders, ethnic groups, religions and who worked in different sectors were included in accordance to legal acts (Equality Act 2010 Chapter 15) and the national guidance (Office for National Statistics, 2012; Office for National Statistics, 2011). The inclusion of all demographics enhanced the research findings in looking for victim characteristics to guide further research.

The Mental Capacity Act (MCA) ensures empowering people to be involved in the decision-making process relevant to them. According to the MCA, a person lacks capacity to consent if the individual face difficulties in making or communicating a decision due to variety of impairments and conditions (Mental Capacity Act 2005). The MCA applies to all people aged 18 or above in England and Whales, and to individuals aged 16 or over who lack the capacity to consent. Additionally, according to the Disclosure and Barring Service (DBS), a child is anyone under 18 years of age (Disclosure and Barring Service, 2015). Hence, due to ethical considerations and to meet the timeline of this study, participants aged 18 or older were included in this study. Targeting this age group is also supported by the findings of the systematic review (section 2.4) which identified a gap in addressing older victims.

3.3.1.4 Inclusion criteria

With reference to the definitions and justification discussed above, the inclusion criteria in the first phase were: individuals aged 18 or over, any gender, any ethnic background, or employment, with a self-reported chronic condition of a minimum duration of three months and residing in the UK with Internet access. To ensure only eligible participants could complete the survey, a pre-screen at the beginning of the survey confirmed the eligibility criteria. Any missing criterion was designed to lead to a “thank you” note and the end of the survey.

3.3.2 Developing the questionnaire

The questionnaire (Appendix 11) was built based on the review of the literature, discussion with experts in the field, and further refined after piloting it (Appendix 15).

The survey started with eligibility criteria related to age, residence and having a long-term condition (section 3.3.1) and a briefing consent form (Appendix 11). The structure and information

provided in the consent form were adopted from previous offline (Sheridan, 2005) and cyber-victimisation (Maple, Short and Brown, 2011) surveys. In order to fill the questionnaire, participants had to confirm by ticking boxes that they understood the information given, the anonymity, the right to withdraw, and contact details for further information or to complain.

The second section was designed to collect demographic information including gender, ethnicity, employment, and county of residence. Demographic information were included in previous studies (Maple, Short and Brown, 2011; Dreßing et al., 2014; Davis, Coker and Sanderson, 2002) for descriptive statistics and to explore a phenomenon. The ethnicity question was self-assigned. Ethnic categories were adopted from the Office of National Statistics because the target population were UK residents (Office for National Statistics, 2011). The main outcome anticipated from this section was sample description and victims' characteristics.

The third section started with asking about the medical condition and self-management plan. The language used to communicate with patients was adapted from previous studies (Davis, Coker and Sanderson, 2002) of people with long-term conditions. In Q12, the participants had to tick their conditions and duration. The participants were given free space to add any condition. It was planned that written conditions Would be further grouped in the analysis to the nearest medical diagnosis based on the International Classification of Diseases 10th version for 2015 available online via the WHO website (World Health Organization, 2017). Participants who had multiple conditions were asked about the condition that affected them most. Question 15 was added to ascertain whether the diagnosis of the chronic condition was made in a healthcare setting. This question was to gap a limitation to the few previous studies examining the relationship between victimisation and chronic conditions which did not consider the diagnosis process (Davis, Coker and Sanderson, 2002). To examine the level of biographical disruption caused by diagnosis (Bury, 1982), Q16 was about the reaction to the diagnosis in terms of fear

level. The options for the self-management plan of chronic conditions in Q17 were developed based on previous studies (Newman, Steed and Mulligan, 2004; Sattoe et al., 2015), evidence-based medicine guidelines (BMJ Best Practice, 2015b; BMJ Best Practice, 2015a), clinical medicine textbooks (Walker et al., 2014; Longmore et al., 2014) and the researcher's clinical experience. An additional space was provided to write all the details about health management. The main anticipated outcomes from this were descriptive statistics on chronic conditions to scope the existing conditions and self-management and to be further cross-tabulated with cyber-victimisation questions.

The fourth section was about cyber-victimisation experience, it started with filtering questions to identify victims of cyber abuse. Communicating the definition of cyber-victimisation to the participants was adapted from previous studies (Dreßing et al., 2014; Maple, Short and Brown, 2011). This section onwards provided free spaces for the victims to share their experiences. Fear and distress were included because it is documented that the psychological effects of victimisation have more impact on health (Dreßing et al., 2014; Short et al., 2014). This section outcome was related to describing cyber-victimisation experience in terms of frequency, means, and perpetrator's identity, in addition to further cross-tabulation with the medical condition. Participants who filled this section were considered to be eligible for the qualitative phase (section 3.4)

The fifth section explored the perceived relationship between having a chronic condition and the experience of cyber-victimisation. The questions explored participants' coping (Dreßing et al., 2014), self-management after the experience, the perceived motivation of harassment (Sentenac et al., 2011a; Sentenac et al., 2011b; Storch et al., 2004). The Stanford standardised efficacy scale (Self-Management Resource Center, 2015) was used because self-management

relies on self-efficacy in taking control of long-term health management (Greenhalgh, 2009), and this is further described below.

The sixth section was about the actions taken by the victims and support received in response to the experience of cyber-victimisation (Maple, Short and Brown, 2011), with particular emphasis on the role of GP (Galeazzi et al., 2009; Kamphuis et al., 2005; Reyns and Englebrecht, 2014). and the role of GP was important in order to identify how to improve health system support. The seventh section invited participants to volunteer for the second qualitative phase (De Korte-Verhoef et al., 2014; Siddiqui and Fitzgerald, 2014).

3.3.2.1 Using a standardised scale

Self-efficacy is a core concept in the self-management of chronic conditions, it represents patients' own beliefs in how capable they are in taking control in managing their health conditions (Greenhalgh, 2009). The researcher included the Stanford self-efficacy scale for the self-management of chronic conditions in Q27 because it is a well-documented scale (Lorig et al., 2000; Lorig et al., 2001). It was first developed in the 1980s and within 10 years it was used in over 100 papers (Ramey, Raynauld and Fries, 1992). Its final modified version is available online for patient education and public use (Self-Management Resource Center, 2015). It is formed of six questions to be answered with a score from 0-10, the average of the six numbers represents self-efficacy of the participant (Self-Management Resource Center, 2015). The researcher aimed to examine the difference in self-efficacy in the self-management of chronic conditions before and after the experience of cyber-victimisation, which could indicate perceived disruption (Bury, 1982).

3. 3.3 Sampling in phase one

The researcher aimed to give the opportunity to every person living with a chronic condition in the UK to participate as probability random sampling gives equal chance of each individual to be selected, resulting in less bias (Bowling, 2009; Seale, 2012). However, equal chances for participants in this study were influenced by the recruitment strategy because gatekeepers were approached in recruitment (section 3.3.4) and of the restriction of having Internet access or the type of condition. Hence, despite the attempt to use a random sample of people with long-term conditions, the researcher does not claim generalisability of findings to others living with chronic conditions. However, the findings gave an idea of the frequency and inter-relationship between having a chronic condition, cyber-victimisation experience and its impact on self-management.

The sample size for a large population (N = 60,000,000) in a cross-sectional study with anticipated frequency (p) of 20%, design effect (DEFF) as 1, and a 95% confidence interval is 246 participants. This was calculated using OpenEpi, Version 3, an open source calculator (Dean AG, 2015) using the equation:

Sample size n = [DEFF*Np(1-p)]/[(d2/Z21-α/2*(N-1)+p*(1-p)]

The prevalence of cyber-victimisation has a wide range between 3.2% up to 92% (Bocij, Bocij and McFarlane, 2003; Dreßing et al., 2014; Maple, Short and Brown, 2011), so 20% was used as the anticipated frequency based on the prevalence of victimisation among young patients living with chronic conditions (Sentenac et al., 2011b). As the research progressed, further variations in the anticipated frequency were identified (section 2.4) and challenges in recruitment were also encountered (section 3.6).

3.3.4 Recruitment strategy

The questionnaire was launched online, this approach is documented to increase the response rate (Boynton and Greenhalgh, 2004), and has been adopted in both offline (Sheridan, 2005) and online (Maple, Short and Brown, 2011) victimisation research. The online approach was helpful in this study because of victims of cyber-victimisation experience social isolation (Maple, Short and Brown, 2011). Additionally, people with chronic conditions might be faced with physical impairments (Quarmby, 2015). Hence, the online distribution also helped to reach remote geographical locations in the UK.

3.3.4.1 Engagement with gatekeepers

Online recruitment was through victim support groups, patient-support groups and social media. Search engines were used to look for victim and health support groups, keywords used included: patient, support, chronic, health forum, disability, hate crime, online support, and specific health conditions' names. The search results were shortlisted, 'gatekeepers' were identified based on the criteria of being: a) established patient and victim support groups/organisation, b) based in the UK or with significant audience from the UK, c) having terms and policies in their websites aligning with ethics to protect participants (British Psychological Society, 2014), d) having direct contact with patients/victims, and e) provided contact details. Further snowballing was followed to reach relevant organisations/charities or journalists, academics and activists in the field. The researcher contacted 'gatekeepers' via email, when no response was received within 1–2 weeks, an email reminder was sent. In cases where a telephone number was provided, further contact via phone was made. Gatekeepers were provided with information related to the rationale of the study, expected benefits to participants in the short and long-term, inclusion criteria, the survey link, study poster and contact details. To generate interest, each time a gatekeeper was

contacted, the request letter was tailored specifically to the audience in that group. Appendix 18 summaries the outcomes of contact, and the researcher reflected on this process in the methodology paper (section 3.6).

3.3.5 Survey analysis

The survey data was collected over 18 months, starting from September 2015 to the end of March 2017. Incomplete responses were recorded after 48 hours from participants' last activity. A total of 424 individuals reached the survey online, 310 of them were eligible, with 222 people consenting to participate and 152 participants completed more than 50% of the survey, this is the final number included in the analysis.

The first step in the analysis was using univariate statistics for descriptive statistics (Katz, 2011) via the web platform and Excel worksheet version 360. The participants reported various chronic conditions and/or disabilities. The demographic data was presented followed by the information on the long-term condition. To ensure the consistency and accuracy in categorising and reporting these conditions, each response was categorised in accordance with the International Statistical Classification of Diseases and Related Health Problems 10th Revision (World Health Organization, 1992; World Health Organization, 2017). Due to variations in terminology used by participants, each condition entry was checked manually and cross-checked individually with the ICD10 classification.

The prevalence of cyber-victimisation was calculated and descriptive statistics of the victimisation experience were represented. Fear was presented on a Likert scale, and grouped into a binary outcome as fear vs. no fear (Dreßing et al., 2014). It is of note that due to the

sensitivity of the issue, questions related to cyber-victimisation were voluntary, hence, the number of respondents in this section was variable.

The impact of cyber-victimisation was described using descriptive statistics and the calculation of the self-management efficacy scale. The self-management efficacy scale of chronic conditions was calculated before and after the cyber-victimisation experience using the Stanford self-management efficacy scale, which is a validated instrument (Self-Management Resource Center, 2015).

The third step in analysing the survey data was through making cross-tabulations between independent variables. Cross-tabulation was first made using Excel sheets version 360 to identify different factors in relation to the scope and impact of cyber-victimisation. Statistical significant tests were performed using Stata 12. The main independent variables were gender, ethnicity, age, disability status, and the impact of cyber-victimisation. The statistical significance was measured using the chi-square test to examine the observed versus the expected number of 2 x 2 tables, with a P value of significance if $p < .05$. The Fischer exact test was used when the number in any cell was less than five (Katz, 2011). To examine victims' characteristics, cross-tabulations were made to highlight the main characteristics of victims, disabled victims, and compare them with the whole sample.

3.4 Phase two

3.4.1 In-depth interviews

3.4.1.1 Sampling of patients/victims

In a sequential mixed methods design random sampling in the quantitative phase, followed by purposeful sampling in the qualitative phase is widely used and well documented (Siddiqui and Fitzgerald, 2014; Krumholz, Curry and Bradley, 2011; De Korte-Verhoef et al., 2014). Due to the lack of information about cyber-victimisation in relation to chronic conditions (Kowalski and Fedina, 2011) and the scarcity of qualitative elements (section 2.4), non-probability sampling was used to give the researcher flexibility to gather knowledge inductively, targeting individuals who meet the criteria relevant to answer the research question (Seale, 2012). Purposeful sampling is a type of non-probability sampling, it is widely used in research and helps in identifying individuals with rich information that inform the knowledge about the research problem of interest (Palinkas et al., 2013). Purposeful sampling can be based on 'criterion I', which means including participants who meet the predominant criteria of interest, or by 'criterion E', which means including participants who do not meet the predefined criteria. Other strategies include taking a homogenous sample or taking the extremes in maximum variation sampling (Palinkas et al., 2013). The 'criterion I' approach was adopted to attempt to include individuals meeting the definitions of chronic conditions and cyber-victimisation in this research (section 3.3.1.1).

In summary, the inclusion criteria were: individuals who qualified for the first phase (section 4.3.1) being aged 18 or over, any gender, any ethnic background, with capacity to consent according to the Mental Capacity Act 2005, living with a chronic condition (With 3 months or more duration and requires self-management, lifestyle or pharmacological), residing in the UK and

currently experiencing or had experienced cyber-victimisation after being diagnosed with a chronic condition.

3.4.1.2 Semi-structured interviews

Qualitative interviewing is a flexible method that allows in-depth exploration of people experiences and beliefs (Britten, 1995). It is one of the methods in research prioritising people's experiences (Groenewald, 2004) and helpful to address the lack of conducting one to one interviews in cyber-victimisation research (Short et al., 2014). The interview guide was prepared (Appendix 12) and ethically approved (Appendix 1) to guide the participants with questions/prompts throughout the interview. Using prompts is a recommended approach to make sure of capturing relevant data to the research question (Seale, 2012). The interview schedule started with taking the participants' written consent (Appendix 13) and explaining the right to skip questions or withdraw (section 3.7). Participants were encouraged to talk first about their health conditions and self-management (Greenhalgh, 2009; Greenhalgh et al., 2011) and their reaction to diagnosis (Bury, 1982; Larsson and Grassman, 2012; Williams, 2000). This was followed by talking about the experience of cyber-victimisation (Short et al., 2014) and its relation to coping and distress (Dreßing et al., 2014). The motives of offenders were explored from participants' perspectives to explore any perceived intentional targeting of people with chronic conditions or disabilities that are documented in the literature (Quarmby, 2015; Sentenac et al., 2011a; Sentenac et al., 2011b). The prompts also included the impact of cyber-victimisation on health and self-management (Dreßing et al., 2014; Short et al., 2014) to ensure that data was relevant to the research question. Coping and support provided to participants were also explored (Reyns and Englebrecht, 2014) to identify areas to be improved in support and cross-check the results in correspondence to data gained from GPs (Kamphuis et al., 2005). At the end of the interview,

participants were debriefed and given the chance to talk about any further information they felt relevant to the study.

3.4.1.3 Recruiting for the interviews

As discussed in section 3.3.2, participants were recruited for interviews via the survey. In the last section of the questionnaire (Appendix 11), participants who agreed to be interviewed had to tick a box and provide their email addresses, or send email to the researcher. The researcher responded by sending the participant information sheet (Appendix 14) and arranging a face-to-face or online interview based on participants' preference as discussed in section 3.7. Cases, where a delusional response was suspected, were discussed with the research team and a list of screening questions for false victimisation was developed (Appendix 16).

3.4.2 Qualitative analysis

3.4.2.1 Interviewing process and transcription

Due to the sensitivity of the topic, the researcher approached each interview (n = 13) with caution and flexibility was required to address the participants' health and emotional needs. The interviews were audiotaped. Some participants preferred a written conversation due to their health needs, such memory issues (n = 1), being emotionally distressed (n = 2) or due to practical issues (n = 3). Audiotaping during qualitative data collection is common practice to assist the researcher's memory and note-taking ability (Guest, MacQueen and Namey, 2012a; Fitzpatrick and Boulton, 1996). However, it is acknowledged that it was not always possible, especially when taking into consideration the sensitivity of the topic. Participants who were interviewed in person or via Skype were asked whether they agree to audiotaping the interview or if they preferred note-

taking by the researcher. All of them agreed to be audiotaped and gave verbal and written consent.

Participants were reminded of their right to withdraw and to share with the researcher if any question made them feel uncomfortable. Throughout the interview process, the researcher offered breaks, refreshments and the option to skip questions. Following the interview, the researcher offered contacts for support channels and a practical self-help book. There was flexibility in following the interview guide, but most participants talked freely, jumping to talk more about their victimisation experience and struggle for help.

Immediately after the interview, the researcher wrote fieldnotes to remember the most important aspects of the interview. This is a common practice in qualitative research to facilitate initial coding and ensure understanding the participant's meaning (Phillippi and Lauderdale, 2018). Real-time interviews lasted between 30 to 90 minutes. Interviews were transcribed verbatim during the same week of the interview to ensure clear transcripts and getting back to participants if any question arose during transcription. This approach also helped in familiarising the researcher with the data and preparing for analysis. The transcript was anonymised, the lines were numbered and the symbol (…) was used to indicate the tenths of seconds paused by the interviewees. The format of transcribed interviews was Calibri, size 11 with a single line and one paragraph spacing between questions. A code was given to each participant, in addition to the time, and the case characteristics.

3.4.2.2 Coding

The first step in the coding was the reading and re-reading of the transcripts several times before formal coding (Braun and Clarke, 2006). This was accompanied by keeping memos in the

form of notes to self to highlight important notes, impressions, and problems that could be used later in the analysis and reporting (Seale, 2012). The coding process was inductive due to the relatively scarce literature in the area and to allow identification of micro and macro issues from the participants' perspective. The process followed the zigzag approach described earlier.

Open coding was employed by examining the data systematically. The researcher looked at the data and started coding line by line, interview by interview. A codebook was developed in response to the research question (Appendix 21), which is an essential step in qualitative research to enhance credibility and reduce bias (Guest, MacQueen and Namey, 2012a). The codebook in this study was developed based on the guidelines provided by MacQueen et al. (2008). The codebook consisted of code definitions, each one comprised the following: code label, brief description, where to use it, where not to use it, and an example from data extracts. The code label is a short prompt to distinguish codes from each other. The short definition is a descriptive phrase that captures the main components of the theme, while the full definition is a descriptive paragraph highlighting the key features in the theme/code, such as conceptual or cultural dimensions. 'When to use' highlighted the textual instances where the code can be applied to data, including double-coding, while 'when not to use' clarified the instances where the code might not be applicable or overlapped with other codes (MacQueen et al., 2008). In addition to these components, the researcher added a label 'relevance to the research question' to ensure that the coding process fitted within the research aim and to avoid being distracted by the richness of qualitative data (Guest, MacQueen and Namey, 2012a).

Codes were applied to data chunks manually by assigning a specific colour. This stage of coding was inclusive, one data extract could be coded using more than one code. The coded data chunks varied between words, phrases, sentences or paragraphs, depending on the ideas shared by the participants and relevance to the research question. After coding the data, codes were

manually allocated to different papers under their specific colours. The codes were further examined in terms of recurrence and were refined into categories.

3.4.2.3 Thematic analysis

The three general aims of analysis were examining commonalities, differences, and relationships (Guest, MacQueen and Namey, 2012b). Thematic analysis was employed because of its theoretical flexibility in this under-explored area (section 2.4). The researcher followed thematic analysis guidance in six steps (Braun and Clarke, 2006). First, familiarisation with the data through transcription, reading, and re-reading. Secondly, the initial coding of all data was systematic as discussed earlier. Thirdly, searching for themes through examining codes. Fourthly, thematic mapping by reviewing and refining themes. Fifthly, defining and naming themes and subthemes. Sixthly, writing up findings with sufficient evidence using narrative and data extracts. It is of note that this process was used in a zigzag approach (Seale, 2012), which helps to define and refine themes during data collection and identify the point to stop data collection (Giacomini, Cook and Group, 2000).

3.4.3 GP short interviews

3.4.3.1 Sampling of GPs

General practitioners were approached in this research because victims of cyber abuse have been documented to disclose this experience to their GPs (Fazio and Galeazzi, 2004; Kamphuis et al., 2005). Additionally, stress is a common complaint in primary care (Apóstolo et al., 2011; Department of Veterans Affairs, 2002) and it is associated with cyber-victimisation

(Dreßing et al., 2014; Maple, Short and Brown, 2011). GPs working in the UK can be regarded as gatekeepers to the referral system required by the victims (Appendix 24). The input from GPs who were not contacted by the victims was also helpful to understand their view from a biomedical point of view (Pinel, 2011; Short et al., 2015a; Kamphuis et al., 2005). Accordingly, the inclusion criteria for GPs were: general practitioners who currently or previously had clinical experience in primary health care in the UK, with or without experience with victims of cyber abuse.

3.4.3.2. Questions to GPs

The questions targeting GPs represented a short written interview, developed taking into consideration the role of GPs in helping both patients and victims (Kamphuis et al., 2005). The questions were also brief to respect the limited time GPs have in the UK (Majeed, 2013). It started with a briefing consent form (Appendix 20) and captured demographic data (Office for National Statistics, 2011). The next section provided the study's definition of cyber-victimisation (section 3.3.1.2), then the first three questions were about any experience the GP might have had with a patient disclosing an online harassment experience (Kamphuis et al., 2005; Fazio and Galeazzi, 2004), while GPs with no such experience were invited to provide their expert opinion in Q4 on the potential impact on health (Pinel, 2011). This was helpful to capture the level of awareness of the impact of cyber-victimisation to improve support for patients and the referral system.

Questions 5 and 6 explored directing patients to online self-management and their responses to it (Lorig et al., 2000; McDermott and While, 2013; Pereira et al., 2015; Sattoe et al., 2015). These questions helped in exploring vulnerability in online health encounters which is usually overlooked (Merolli, Gray and Martin-Sanchez, 2013). At the end of the interview, GPs were invited to write any information they considered relevant to the study, and contact details were provided for further information.

3.4.3.3 Recruitment of GPs

Online recruitment is documented to increase response rate (Boynton and Greenhalgh, 2004), especially with GPs in the UK who are recognised as having very busy schedules (Majeed, 2013). Doctors are active social media users (Brown, Ryan and Harris, 2014) and this is acknowledged by the British Medical Association (BMA) guidance on the ethical implications of using social media (British Medical Association, 2018). Gatekeepers were approached to help in reaching GPs via mailing lists and social media, in addition to snowballing of contacts. Out of 16 gatekeepers approached, nine helped in reaching GPs, seven of them were GP groups or organisations, and two were snowballing connections. Appendix 18 summarises the groups approached and their responses.

3.4.3.3 Analysis of GP responses

The same codes developed in the codebook (Appendix 21) were applied. The coded data chunks were categorised to identify emergent themes as described in section 3.4.2. This approach helped in linking the qualitative data with each other and allowed triangulation.

3.5 Piloting

The survey, interview guide and GP questions were piloted before commencing the data collection. Minor changes were applied to layout, wording and order of questions. Additionally, the phases of research informed each other to modify questions. The data from piloting was relevant in terms of reflecting the scope and impact of cyber-victimisation. Hence, it was useful in ascertaining the participants' understanding of questions and the input to the study. The importance of piloting is discussed in Appendix (15). Piloting the online survey is addressed in

Appendix (15). Piloting the interview guide is available in the appendix (17). Piloting GP questions is summarised in Appendix (19).

3.6 Reflection on methodology and recruitment

The researcher's reflection of the challenges that faced the recruitment process in this study were covered in section 3.6.

3.6.1 Using an online approach

In this study, an internet-based approach was employed with the purpose of providing: a) a platform for a mixed-method online survey; b) a primary mean to contact gatekeepers and provide relevant information on the research to generate interest; c) a means to disseminate and publicise research links via social media, e-newsletters and mailing lists; d) a method to allow volunteering by interested participants, via email, to arrange for in-depth interviewing; e) an alternative approach in interviewing by providing virtual interviewing (e.g Skype) as an option, if preferred by participants. The Internet was used to facilitate this research because online methods are recommended to increase response rates (Boynton and Greenhalgh, 2004). Additionally, there were specific reasons to adopt online approaches with this particular target population because cyber-victimisation victims experience from social isolation and fear (Maple, Short and Brown, 2011) and people with disabilities might face physical challenges in travelling (Quarmby, 2015; Sunderland et al., 2014), which in both cases could limit reaching potential participants. However, reaching the participants was also influenced by the inclusion criteria and overall study design as discussed below.

3.6.2 Recruitment challenges

A total of 84 gatekeepers were approached to help in recruiting participants for this research, and 55 (65.48%)) accepted to help as summarised in Table 2. Acceptance implied actively publicising the link to the survey via social media, newsletters, web pages or mailing lists. It is estimated that each gatekeeper generated interest from 0-3 participants.

Table 2*. Categories of gatekeepers approached for recruitment and their responses in n(%)*

Gatekeeper Category	Accepted	Declined	Pending	Total
Patient support groups/organisations	21	11	13	45
Victim support groups/organisations	22	0	1	23
Other groups	12	1	3	16
Total	55 (65.48%)	12 (14.29%)	17 (20.23%)	84 (100%)

To reflect on the recruitment process, the responses from gatekeepers and subsequent interactions by the respondents were examined. The sources of data included: 1) responses from gatekeepers received via email, phone calls or social media interactions, 2) responses from participants which were in the form of written or verbal feedback before or during interviews, 3) researcher's notes and observations following each wave of recruitment by individual gatekeepers. As the aim of this section is to reflect on methodological challenges and guide future research, we grouped all these responses and looked for patterns to identify challenges or facilitators of using online research methods with people with long-term conditions who were victimised. The responses were read and re-read, and further categorised in an approach sympathetic to thematic analysis (Braun and Clarke, 2006). The recruitment and data collection

were challenged by four overarching themes: social identity in online support groups, the role of online gatekeepers, the contradictory role of social media, and promoting inclusivity.

3.6.2.1 Social identity in online support groups

Social identity was identified as a factor influencing reactions in virtual communities. Viewing oneself as a disabled person, victim, or having an invisible disability or a mental health condition revealed higher motivation to participate. Participants who identified themselves as "disabled" were more responsive to communication especially when they were enrolled in groups working against disability hate crime. Having an "invisible disability" also seemed to influence participants' attitudes towards sharing their experiences. This was seen particularly in online patient support groups; people with invisible disabilities were co-operative in making their voices heard. They seemed to be struggling to legitimise their conditions and challenge the prejudice and hostility against them. One of the participants with Myalgic Encephalomyelitis (ME) shared:

> 'The online ME community are marvellous. We support each other. The ME community is almost unique in that, by the nature of the condition, we are almost entirely online, so are very protective of each other, and very quick to dismiss and discredit the numerous snake oil salesmen and false friends. Another unusual aspect of ME is that we are fighting a battle against the psychosocial model that has been foisted on us. Although ME is classified by World Health Organisation as a neurological condition, in UK it is treated as psychological, so we are always fighting the misinformation, medical mistreatment and belittling of our condition. Many of us have become this ill because we pushed ourselves too hard when we first became ill (…) We fight well, despite being so ill.' (Participant B4)

Participants who identified themselves as "victims" were also keen to participate, this was specific to cyber-harassment victims who just wanted to be heard. They shared their experiences in a detailed manner and explained how negative internet interactions had a real impact on their lives. People recruited from mental health support groups shared the same appreciation towards being heard. However, other online groups' members were cautious in dealing with "outsiders",

being academics or healthcare professionals. This was revealed during recruitment arrangements when a participant - who was also a gatekeeper- explained how the word “spoonie” reflects their experiences more than medical terms. Spoonie is a term adopted by people living with chronic illnesses and disabilities. The name came from ‘’The Spoon Theory’’ which was first described by a blogger living with lupus, she used spoons to illustrate to her friend the limited choices people with chronic conditions face in their daily life. The term spoonie was then derived and largely adopted by people with chronic illnesses and disabilities in online communities.

3.6.2.2 The role of online gatekeepers

Online-gatekeepers had a challenging role in reaching participants with disabilities. This was based on the size of the organisation/group, fees and funding issues, type of audience, and the role of volunteers. Most well-established organisations with thousands of members in their online communities had a pre-determined policy in responding to research requests, for example, having an online form to ask for help in recruitment. Responses from these organisations took time but was instrumental in reaching high numbers of eligible participants, however this did not necessarily result in actual participation. Another challenge linked to gatekeepers of large online communities was issues related to fees and funding, which was mostly faced with patient-support groups. Some organisations declined the help request because their social media accounts support only to research funded by their establishment, while other organisations requested fees to publicise research with them.

The type of audience associated with gatekeepers also influenced the decision to support recruitment. Some patient-support groups were protective of their members, this was seen in some groups for chronic illness and physical disabilities who declined due to data protection

issues. While one gatekeeper supporting people with mental health conditions and intellectual disabilities was protective of members due to uncertainty about the capacity to consent. However, gatekeepers from victim support groups and charities were very responsive and prioritised sharing the research with their members as a mean of support to them.

In cases where gatekeepers were volunteers in charities who were themselves coping with disabling conditions, the response was influenced by gatekeepers' health condition and previous victimisation experiences. The responses ranged from showing interest but apologising due to health and human resources issue, to acceptance and dissemination of research links especially in the case of invisible disabilities.

3.6.2.3 The contradictory role of social media

Using social media accounts to promote the link to the survey depended on the 'right' pages to share or tweet the call for participants. Facebook and Twitter accounts were used, but Twitter was generally more effective in reaching the target population. When gatekeepers' accounts tweeted the link to the survey the response from online followers was immediate. However, immediate response means two or three people interacting with the research link out of thousands of followers per each tweet. The effect of the tweet was also short-term; it did not exceed a few hours after which no more interactions, i.e retweets, were observed.

Social media accounts of activists trusted by people with disabilities such as disability-support groups, disabled bloggers, or active journalists against disability hate crimes resulted in snowballing of the link. These were as effective as larger established support groups' accounts. Tweets by popular academics in health or cyber abuse areas resulted in further interactions by

academic and professionals but did not necessarily reach eligible participants. Hence, the use of any hashtag related to #spoonie reached the targeted population more than scientific words.

3.6.2.4 Promoting Inclusivity

Inclusivity appeared to be a potential advantage of using online-recruitment and interviews. Online dissemination of the survey link helped to reach diverse participants and remote geographical areas, which could reflect diverse victim experiences. When in-depth interviews were conducted, inclusivity was promoted by providing virtual interviewing via Skype as an option. This alternative was preferred by most of the participants. People with disabilities implied that online interviewing accommodated their needs in terms of physical mobility, time constraints, or to avoid exhaustive traveling. Furthermore, inclusivity was addressed in cyber-harassment cases by overcoming victims' social isolation. This was through giving them the chance to participate despite their fears of safety and/or social anxieties following this traumatic experience. Some victims explicitly shared their fears while planning for the interview and others created new Skype accounts to ensure helping others by informing this research. Despite these observed benefits, inclusivity was also a challenge due to the heterogeneity of conditions categorised as disabilities, which required the researcher to be sensitive to individual needs. For example, one participant with a physical impairment preferred online interviewing, but they also had a communication impairment and so being able to type answers enabled their participation.

3.6.3 Discussion on recruitment challenges

Using online-based approaches in recruiting participants from 84 patient and victim support groups have revealed a number of challenges and advantages of using these methods with people having long-term conditions and disabilities in cyber-victimisation research. These were related to the target population, gatekeepers and the use of social media.

One of the main challenges identified was the existing online identity of participants. Being a victim, disabled, or having an invisible illness appears to increase the motivation to participate in research. Disability identity is a known area of research, it could be defined as the positive sense of self and feelings, it helps to cope, and find solidarity with the disabled community (Dunn and Burcaw, 2013). In this study, participation could be influenced by representing the identity of disabled and/or victimised groups, to express the group's opinion or help in improving support to them by sharing own victimisation experiences. Some of the key aspects of disability identity described in previous studies were finding a personal meaning, attachments in disability group membership, and being a target of discrimination (Dunn and Burcaw, 2013). Discrimination as part of the disability identity is consistent with our findings, however, the role of online communities could have influenced the representation of this part of self-identification. For example, a previous review of challenges in using online methods with students having disabilities identified a possible bias in representing self because disabled students tended to provide a positive self-image (De Cesarei and Baldaro, 2015). Nonetheless, in this study there was a complexity of representing self as a disabled person and a victim, this could have resulted in affirming disability status and using the illness experience for self-expression as will be covered in Chapter 4. This was further supported by the role of online communities which empowered disabled people to confront discrimination.

The presence of identity across identified challenges could be explained by the Social Identity Theory, in which the personal image is enhanced through group membership, resulting in an “in-group” and an “out-group” categorisation with a tendency of bias towards the in-group (Tajfel, 2010; Turner, Brown and Tajfel, 1979). Based on this explanation, illustrated in Figure 6, people with disabilities go through the process of developing a personal identity followed by social categorisation. In this process the in-group is the disabled community. When being part of this community the outcome of inter-group comparison process results in empowerment and encourages participation in research. Alternatively, not identifying self as part of a disabled in-group could result in perceived discrimination and further isolation from the community or other activities such as research.

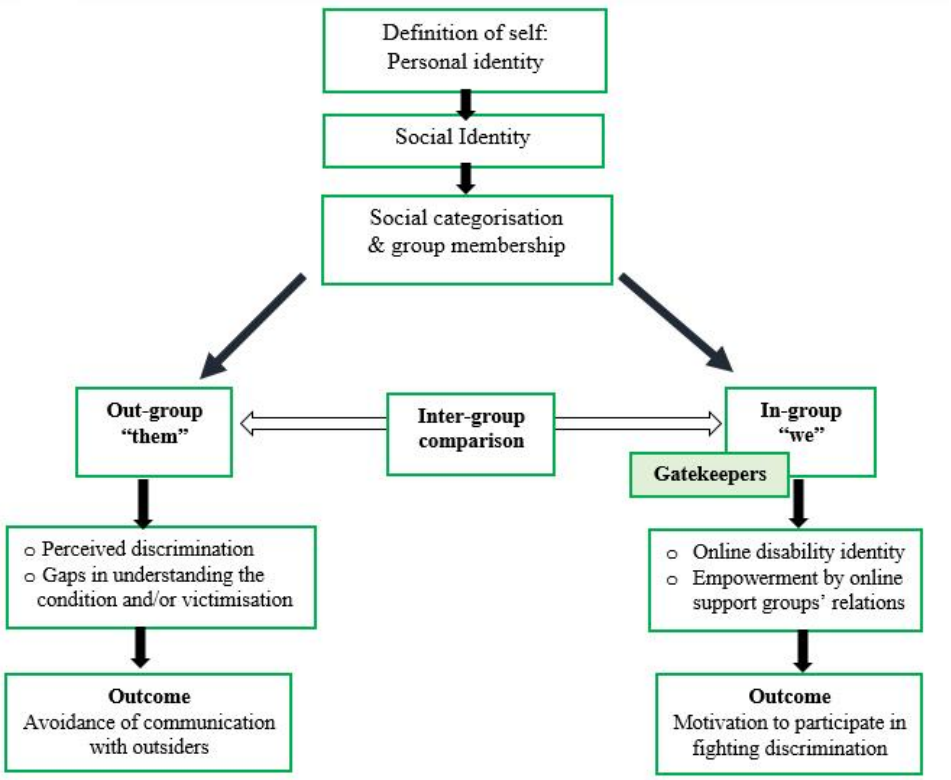

***Figure 6**. Social Identity Theory and cyber victimisation of people with chronic conditions and disabilities, adopted from (Turner, Brown and Tajfel, 1979)*

The identification of specific aspects of online self-representation of disabled people was recommended in previous research (Molin, Sorbring and Löfgren-Mårtenson, 2015), and if accompanied by highlighting the positive aspect of online identity (Dunn and Burcaw, 2013) improvements in research methods could be seen. Hence, in this study, we observed how having an existing online identity related to victim status or certain disabilities maximized the potential of involving people at risk to enhance their voices in research.

The online identity of people with disabilities can also be a barrier to participation; differences between the target population and the researchers/academics were recognised.

These differences were mainly seen in interactions with social media accounts and in terminology used. Participants reacted to the requests publicised by people fighting for their cases such as activists against disability hate crime. Hence, pre-established relations and trust could have influenced the decision to participate. This highlights the need for mutual-trust for a productive recruitment process (Cohn, 2015). While considering the terminology used, adjusting hashtags to adopt terms common among disabled people such as #spoonie, resulted in higher engagement by participants, but the use of this term was very limited in the academic literature. Upon further search on the use of the word spoonie -and its derivatives- in social media, it appeared to be used widely by users to refer to disability and chronic illness (Miserandino, 2003). While upon searching in research databases very few results hardly mention The Spoon Theory, such using it as an example of internet activism (Dingwall-Jones, 2014) or to discuss the need to understand the illness experience (Biro, 2012; Jackson, 2013). In a published dissertation, disabled participants brought The Spoon Theory in their narratives to communicate and express themselves (Miller, 2015), which was encountered during this study too. Hence, understanding how people with disabilities represent themselves and trust-building in research are necessary in online recruitment and in designing future research.

This section addresses those methodological concerns regarding the role of gatekeepers. It is documented that gatekeepers could assist in reaching disabled participants, however, gatekeepers' role in literature was considered challenging because of delaying research, or denying the opportunity to participate due to over-protection (Goldsmith and Skirton, 2015). In this study, the over-protection was anticipated from victim support groups due to the sensitivity of the topic, and from groups for people with mental health illness and intellectual disabilities due to Due to communication issues, the MCA states that people with ID have capacity unless proved otherwise. However, upon contacting the gatekeepers protection came from support groups for

chronic illnesses and one group for people with intellectual disabilities. While groups supporting victims of cyber abuse who experience PTSD and other mental health consequences were more motivated. This could be explained by these groups' sympathetic aims to support participants or could be linked to the social identities too. This is because groups using medical conditions to represent themselves are already legitimised to the public compared to groups of people having invisible illnesses or victims of online abuse. Further, cyber-victimisation is only recently recognised, its impact on disabled people is under researched, and there are assumptions by informal and formal support channels underestimating the impact of what happens on the internet (al-Khateeb et al., 2017). These assumptions undermine social support, which is necessary for victimized disabled people (Fridh, Lindström and Rosvall, 2015). Hence, these factors could have encouraged victim support groups to help in recruitment of this research as explained in section 3.3.4.

Further to trust and status legitimisation in relation to gatekeepers, another documented challenge is perceived power imbalance and priorities between gatekeepers and potential participants (Carlson, 2013; Goldsmith and Skirton, 2015). It is possible that online recruitment minimised this imbalance because in our study participants who saw their gatekeepers promoting the study on social media did not necessarily interact with the link. Gatekeepers' role was also limited by funding issues, which is a documented concern in previous research when the gatekeepers had different agenda from researchers (Wiles et al., 2007). This was further complicated in some cases where the online identity and gatekeepers' agenda aligned, but capacity and resources available were scarce. This issue is also consistent with previous work showing how gatekeepers might limit access to participants when their resources are limited (Nind, 2009).

The potential of using online research methods was promising in terms of addressing inclusivity and diversity people with disabilities and victims. This research confirmed previous work suggesting the role of online methods to reach people with disabilities with less cost and encourage disabled people to talk openly more than face to face (Morris, 2013; Sunderland et al., 2014). Such an approach helped in addressing diversity but did not guarantee high numbers of participants probably due to the sensitivity of the topic in this study. However, online methods responded to the risk accompanying being a disabled person and a victim of cyber abuse by overcoming fears and physical, social, or emotional barriers.

It is to be acknowledged that one of the main research approaches to tackle oppression and improve inclusivity is community based-participatory research. It could be considered as a partnership between the researcher and the researched in which the knowledge results from peoples' participation in defining issues of concern to them and solving them (Bate, 2000). Participatory research makes no definite discrimination between the researchers and researched (Meyer, 2000). Participatory research is a powerful tool for researching with disabled people because of its values of empowerment and contribution to social change (Nind and Vinha, 2014). It challenges exclusion in the research process by involving people with disabilities to develop the research project, conduct and analyse data in a continuous cycle of learning (Buettgen et al., 2012). The participatory research was also used to create accessible instruments for individuals with developmental disabilities (Nicolaidis et al., 2015). My study is one of the first studies to examine cyber-victimisation of people with different types of disabilities, and due to the sensitivity of the issue, a preliminary scoping of the phenomenon and sensitive approach to victims were needed, hence a participatory action research could not be fully adopted. However, our findings will help in designing further research with participatory nature and higher chances of engaging participants at all stages of the research process.

The discussed challenges and advantages in this reflection on the recruitment process are limited by a number of factors. Similar to other research (Morris, 2013; Carlson, 2013), one limitation is the inadequate opportunity given to participants with intellectual disabilities due to their gatekeepers' responses or their capacity to consent. This could be overcome by tailoring consent and content to their needs and offering sufficient support, which could be challenging (Goldsmith and Skirton, 2015). Another limitation is accessed by people with visual and motor impairments because the format or length of questions could be tiring or require further adjustments (De Cesarei and Baldaro, 2015). Other key limitations applicable to online research methods include lack of access to the Internet and socioeconomic status (Sunderland et al., 2014). Despite these challenges, this section could provide an insight into the potential of using online research methods with people at risk and will guide future research to do further modifications to ensure overcoming the identified challenges.

3.6.4 Opportunities and challenges in interviewing

In-depth interviewing with the participants in this study had offered beneficial opportunities and also challenges, which mostly depended on the mode of interviewing. Face-to-face interviews indicated participants' motivation to travel and have a conversation about their experiences, and this was without monetary incentives. For example, participant B7 has a physical impairment and social responsibilities but she was keen to participate and eager to share her story. In face-to-face meetings, I was more confident in observing the participant's reaction to discussing such a distressing experience and offering support. However, meeting in person also carried the risk of being followed and fear of being exposed to the harasser, especially when the cyber-victimisation was ongoing.

Virtual interviewing was more advantageous than a physical approach in the cases where it was impractical or difficult for the participant to travel. It promoted inclusivity by providing a suitable alternative, as in the case of interview participant B8. However, in virtual interviewing some participants were too scared, had to change their Skype IDs, and sometimes the participants did not show up on time and the interview had to be re-scheduled, as in the case of participant B6. Phone interviews were an alternative to the face-to-face approach, which proved helpful when the participants were too scared to log into Skype. The challenge was faced with participant B2, because the phone helped to overcome travel issues, but it also involved phone line clarity issues and appreciating differences in accents. This was overcome during the transcription process and verification by the participant.

Written interviews were the last alternative to get the participants' input. Surprisingly, written experiences were detailed, with long responses and helped the participants to respond at their own pace and time. The written interview was particularly beneficial with participant B4 due to impairment issues that could exclude the participant from research that strictly requires immediate responses. It is to be noted that visually observing the participants was missed in phone calls and written interviews, however, the participants and this study benefited from these alternative ways to promote inclusivity.

3.7 Research integrity

3.7.1 Formal ethical permissions

Ethical approval was obtained from the University of Bedfordshire, Institute for Health Research Ethics Committee 24th of July 2015 (Appendix 1). Further communications were made with the NHS Research Ethics Committee (REC) (Health Research Authority, 2015) (Appendix

2), and the Disclosure and Barring Service checks (Disclosure and Barring Service, 2015) (Appendix 3). It was concluded that no further permissions were required

3.7.2 Ethical considerations and risk assessment

Cyber-victimisation is a sensitive issue associated with fear and distress (Maple, Short and Brown, 2011), which interferes with the 'victim's' everyday life and wellbeing (Dreßing et al., 2014). A full risk assessment was made to ensure no harm was caused to participants, protecting them, promoting goodwill and to respect their autonomy (Wiles, 2013a; Department of Health and Social Care, 2005; British Psychological Society, 2014). The risk assessment in Appendix 10 helped in respecting the participants' autonomy by giving them the opportunity to express self and make decisions on sharing their experiences and how, with considering the possible consequences in being involved in a sensitive research. The survey began with a briefing information and written consent. The interviews started with an information briefing, followed by consent; both written and verbal consent. Anonymity, confidentiality and the right to skip questions or withdraw at any time without giving a reason were explained to the participants. During the interviews, the risk of causing distress when discussing a sensitive topic was considered as detailed in Appendix 10. This was addressed by observing participants' reactions to prompts, reminding the participants of their right to skip questions, postpone interview or to withdraw without giving a reason. Another risk was the potential physical harm in ongoing cases. To mitigate this, the time and place of the interview were planned to take place in a neutral place, such as a university campus, and during working hours, in addition to offering virtual interviewing as an alternative. The participants were debriefed and contact details were provided for further information or to complain. Upon participation, further support was available to the victims in terms of practical advice, reading materials and contact details of some helpful organisations. The sections below provide a detailed discussion of the ethical considerations.

3.7.2.1 Cyber-victimisation as a sensitive issue

Cyber-victimisation is a sensitive issue associated with fear and distress (Maple, Short and Brown, 2011). It also interferes with the victim's life at several levels starting from health, social isolation, economic impact of changing work or unemployment and long-term physical or mental health impact (Dreßing et al., 2014). This might result in psychological distress upon recalling such experience. Research involving psychological distress and exploring sensitive topics, such as illegal behaviour, sexual behaviour, and violence, is classified to have more than minimal risk to participants (British Psychological Society, 2014). In research involving human participation, risks, harms, and benefits should be assessed early and weighted against each other (Wiles, 2013a; Department of Health and Social Care, 2005). A 'risk' is defined by the BPS as 'the potential physical or psychological harm, discomfort or stress to human participants that a research project may generate' (British Psychological Society, 2014, p.13).

Appendix 10 summarises the primary risk assessment in this study. However, risks and harms might not be completely predictable (Wiles, 2013a), so in addition to primary risk assessment, there were continuous ethical considerations throughout the research process.

3.7.3 Ethical issues related to participants

3.7.3.1 Working with people at risk

There is often a tension between participants' needs and academic or research requirements when working with people at risk (Aldridge, 2014). This is mostly when the researchers employ a top-down approach with less input from the participants, for example when the research is influenced by input from funding bodies. To overcome such tension, this study was phenomenologically informed to examine the human experience (section 3.2.1), in which the

priority was given to the qualitative input from the participant (section 3.2.2.1), which is consistent with the research concerned with people at risk (Aldridge, 2014). Further, the engagement with gatekeepers helped in having a flexible research in which the gatekeepers were supportive in recruitment (section 3.6.2.2), and provided a participatory element for health promotion (section 6.3.2).

The discourse of "vulnerability" in research ethics is multifaceted. The term 'vulnerability' was widely used in research to imply a status given to participants who required special protection by researchers and ethics committees (Levine et al., 2004). It was first used to describe children aged less than 16 years or individuals who do not have the capacity to consent according to the Mental Capacity Act (Mental Capacity Act 2005), or with unequal power relations (British Psychological Society, 2014). Defining vulnerability was arguably broadened to include individuals living with disabilities or long-term life-threatening conditions (Kipnis, 2001). This caused further consequences on research ethics.

Connolly (2003) discussed a group of principles for research with "vulnerable" groups, these included explaining the focus of research to participants, researcher's sensitivity and response to participants' distress, and the dissemination of findings. These principles were considered in this research at the risk assessment stage (Appendix 10). However, broadening the definition of "vulnerability" led to an unclear demarcation between vulnerable and non-vulnerable groups (Levine et al., 2004). Thus, Aldridge (2016) argued that such general definitions of vulnerability in research lead to labelling the participants, exclusion and undermined research. The labelling aspect was addressed in the MCA and the term "vulnerable adult" was replaced by "adult at risk" (Mental Capacity Act 2005). In this study, it was acknowledged that the definition of vulnerability is troublesome when working with people who experienced cyber-victimisation, because of the ongoing challenges to get support (section 2.3.4). To mitigate this, inclusivity and participation are

recommended in the research involving marginalised groups (Aldridge, 2016). The researcher was inclusive in defining participants as a ‘at risk group’ to protect participants from emotional harm as a result of recalling cyber-victimisation experience, inclusivity was further discussed in section 3.6.2.4. Moreover, this research incorporated a participatory approach in health promotion design and dissemination (section 6.3.2).

3.7.3.2 Psychological and emotional harm

Cyber-victimisation is a disturbing experience often associated with PTSD and recalling it may cause distress (Dreßing et al., 2014; Maple, Short and Brown, 2011). In the qualitative phase of the study, possible psychological or emotional harm was anticipated as a collateral to data collection.

The participants were given the choice not to answer any question they felt uncomfortable to talk about, this was encouraged by explaining to them to say ‘pass’ to skip this question without giving a reason, which is a documented strategy in qualitative research ethics (Wiles, 2013a). This information was available to them in the participants’ information sheet (Appendix 13), which was sent prior to the interview. It was also part of the consent form (Appendix 14), which was in a written form before the interview. The researcher also explained the right to skip or withdraw verbally to participants prior to the interview and ensured whether they had further questions (Wiles et al., 2005).

In the case of unintended psychological harm, the researcher considered postponing the interview and reminded participants of their choice to withdraw at any stage of the research without giving a reason (Connolly, 2003). The victims were given the choice of retrospective

withdrawal after declaring an interest in participation before and up to two months after the interview date.

Additionally, participation in this study was potentially beneficial to participants when they felt they were listened to (Wiles, 2013a), especially cyber-victims who may face difficulties convincing others about the seriousness of their situation (Galeazzi et al., 2009). Untrained counselling of distressed participants might harm participants psychologically (Connolly, 2003). The researcher recognised that participants need professional support from trained personnel, which is beyond the researcher's expertise and boundaries. Hence, the researcher attempted to be generally sensitive towards the participants (Connolly, 2003), giving general advice and providing a contact list of relevant supportive agencies available to help, including the National Stalking Helpline, Victim Support, the police, patient support groups and the NHS. The participants were also offered a copy of a practical help book titled "A Practical Guide to Coping with Cyberstalking" (al-Khateeb et al., 2015).

3.7.3.3 Physical risks to participants

This research did not include invasive biomedical tests or testing the effectiveness of a treatment. However, there was a possibility of emotional distress when in-depth interviews took place. In general, physical violence in cyber-victimisation cases is less compared to offline cases (Short et al., 2014). This slight risk was considered in case the interviewee was still experiencing harassment and this was combined with offline victimisation, where there was a possibility that the victim was being followed by the offender to the interview. To address this issue, the researcher assessed the risk of physical violence based on the status of cyber-victimisation as 'ended' or 'ongoing', and gave the participants the choice of conducting the interview in a neutral public place such as a university or online via Skype.

3.7.3.4 Assessing practical issues

Practical issues included choosing a place and time for interviews (Wiles, 2013b). The researcher attempted to plan a date and place that suited the participants' schedule, respect their privacy and protect them from harm (Connolly, 2003).

Another practical issue was travel expenses. The use of monetary incentives is controversial in research because it may influence participants' behaviour towards the study (Seale, 2012). Approximately 84% of the UK population has daily access to the Internet including deprived communities (Office for National Statistics, 2014), hence the alternative to travel was offering an online interview to adapt to participants' needs.

3.7.3.5 Participants' autonomy and consent

Participation was voluntary and the participants were free to withdraw at any point without giving a reason (Connolly, 2003). Data were completely anonymous and were kept confidential. Written consent (Appendix 13) was taken for audiotaping the interview or taking notes (Department of Health and Social Care, 2005). Recordings were transcribed anonymously and will be deleted after completion of the study and documenting of findings.

In the case of questionnaires (Appendix 11), before commencing to answer the online questions, the first section contains information related to the research and contact information for complaints or further enquiries. Participants had to confirm that they read and understood the information and understood their right to decline (Connolly, 2003) before answering any questions.

3.7.3.6 Risk in publishing the findings

It was anticipated that victims might feel at risk of exposing their identities when they filled in the questionnaire in the first phase (section 3.3) or when they gave in-depth information in the second phase (section 3.4). Prior to participation, the researcher explained that the data would be completely anonymous and could not be traced to the identity of the participant (Sheridan, 2005). Written consent was taken to use a summary report of quantitative data and anonymised quotes from qualitative data (Department of Health and Social Care, 2005). Contact information was available to participants if they had enquiries, complains or were interested in the research findings.

3.7.3.7 Ethical dilemma

There was a possibility of encountering an ethical dilemma during data collection. Ethical dilemmas happen when the researcher receives information that raises concerns, but is asked to keep them confidential (Wiles, 2013a). The anticipated scenario was interviewing a victim who is still experiencing cyber-victimisation, but had not sought support. Another scenario was the case of deterioration of health status secondary to this experience. The researcher planned to provide advice about the available channels of support and encourage the participant to seek help. However, if the participant refused to ask for help, then the challenge was about confidentiality versus having an individual who is at risk or with deteriorating health. The plan was to assess the seriousness of risk to the participant of each case (Connolly, 2003). No ethical dilemmas were encountered. However, one victim was in need of further support and this was communicated confidentially with the supervisory team, experts in the field and members of the ethics committee.

3.7.4 Ethical considerations related to GPs' participation

To adapt to the increasing pressure on GPs to deal with patients and improve access to services (Majeed, 2013) and the requirement of seeing each patient in 10 minutes (Royal College of General Practitioners, 2013), the time of GPs was highly respected. GPs were invited to participate via social networks and online discussion forums to complete a written interview with short brief questions (section 3.4.3).

No personal data were gathered about GPs or their patients, and anonymous answers were collectively analysed and reported. The first group of questions (Appendix 20) included a description of the study with contact information for complaints or further queries. It was followed by written consent taken by confirming that they understood the information provided. Participation was voluntary with the freedom to withdraw at any point.

3.7.5 Risk to the researcher

3.7.5.1 Physical risk to the researcher

The context was generally not dangerous, and the participants were not violent, addicts or criminals. There were some possibilities of physical risk in the case when the interviewee was followed or the interviewee was a false victim. To anticipate these issues, the interviews were held in a neutral place such as universities and virtual interviewing was offered. Interviews were attempted to be anytime between 9 am to 5 pm to be within the university working hours. The researcher provided the time and place for the interview with colleagues, in addition to the expected duration of the interview and return to inspect any delay (Wiles, 2013a).

3.7.5.2 Risk of being targeted

Cyber-victimisation researchers might end up being targets of abuse after being involved in this phenomenon. Stalking of health care professionals is more common than stalking in the general population (Mclvor and Petch, 2006). To prevent this, the researcher only used university email and strict privacy settings in personal accounts. The researcher kept the professional communication with participants via university email, attempting to work with the victims as partners with respect (Connolly, 2003).

3.7.5.3 Emotional risk to the researcher

Researching sensitive topics can constitute an emotional pressure on the researcher (Dickson-Swift et al., 2009). Thus, listening to narratives of a distressing experience and its health consequences like cyber-victimisation had the potential to leave the researcher with emotional distress. To anticipate this issue, the researcher attempted to set at least two day intervals between interviews (Wiles, 2013a), in addition to the strategies identified in the risk assessment (Appendix 10).

Emotional trauma can also result during transcription due to recurrent listening to sensitive recordings (Kiyimba and O'Reilly, 2015). Other advised approaches to deal with it include informal debriefing with friends or family (Dickson-Swift et al., 2009). In such cases, the researcher was obligated to participants' anonymity and confidentiality. Other proposed strategies included formal counselling sessions (Connolly, 2003). However, the researcher only considered this in the case of severe distress, which was not applicable due to the previous clinical work experience in psychiatric wards.

3.7.5.4 Researcher's position and medical background

Researchers should recognise their professional boundaries (Connolly, 2003). The medical background of the researcher was considered and the researcher answered only general questions related to health, while questions from patients related to the personal management plan were advised to be shared with their physicians.

3.8 Summary

This study employed a mixed-method phenomenologically-informed research design. The sequential design started with a first phase, represented by an online survey to inform the scoping and sampling of the qualitative part of the second phase. The second phase included in-depth interviews with patients/victims, and short written interviews with GPs. The priority was given to the qualitative phase, while the integration and triangulation were implemented throughout the design. The findings will be presented separately in the results chapter and integrated in the discussion chapter.

Chapter 4

Results

4.1 Introduction

In this chapter, the findings from each phase of this study will be presented. The survey results will be organised as follows: demographics, the experience with chronic conditions, cyber-victimisation experience, the impact of cyber-victimisation and support. This section also includes cross-tabulations and comparisons between the sample, the victims, and victims with disabilities. The second section reports the themes which emerged from the qualitative data, while the third section presents the results from the GPs' data. Finally, all these results will be presented in a health promotion tool, in addition to a description of the tool, its development, and the participatory process to collaborate with the victims and gatekeepers to improve it.

4.2 Quantitative results

4.2.1 Situating the sample

A total of 152 people with long-term conditions participated in the study. The sample was diverse in terms of gender, ethnic background and age. Most participants were female 120 (78.95%), with 29 (19.08%) male participants, and 3 (1.97%) did not want to specify their gender.

The ethnic background of participants varied, the majority 131 (86.18%) were from White ethnic backgrounds, 11 (7.24%) from Asian ethnicity, 4 (2.63%) had a mixed background, 3 (1.97%) were Black, and 3 (1.97%) from other/Arabic background. Table 3 provides a detailed breakdown of each ethnic group corresponding to the ONS guidelines as described in section 3.3.2.

***Table 3**. The ethnic diversity of the participants (n = 152)*

Ethnicity	Count	%
White	131	86.18%
English / Welsh / Scottish / Northern Irish / British	121	79.61%
Irish	1	0.66%
Gypsy or Irish Traveller	0	0.00%
Any other White background	9	5.92%
Mixed	4	2.63%
White and Black Caribbean	1	0.66%
White and Black African	0	0.00%
White and Asian	1	0.66%
Any other Mixed / Multiple ethnic backgrounds	2	1.32%
Asian	11	7.24%
Indian	2	1.32%
Pakistani	4	2.63%
Bangladeshi	2	1.32%
Chinese	0	0.00%
Any other Asian background	3	1.97%
Black	3	1.97%
African	3	1.97%
Caribbean	0	0.00%
Any other Black / African / Caribbean background	0	0.00%
Arab	3	1.97%
Any other ethnic group	0	0.00%
Total	152	100%

The age range of participants was 18 to 65 years with a mean age 34.74 (SD = 12.98) and the majority (43.42%) were between 18 to 29 years. However, the age distribution included

participants from different age groups, with participants aged 30 to 39 years comprising 21.71% of the sample and those aged 50 years or more were 16.45% of the sample. The age groups are broken down in Table 4.

***Table 4**. The age groups of participants (n = 152)*

Age group	n(%)
18 -19	16 (10.52%)
20-29	50 (32.89%)
30-39	33 (21.71%)
40-49	28 (18.42%)
50-59	15 (9.87%)
60+	10 (6.58%)
Total	152(100%)

The majority of participants 74 (48.68%) did not consider themselves as following a particular religion. The rest of the sample was as follows: Christians 46 (30.26%), Muslims 11 (7.24%), Jewish 3 (1.97%), Hindu 3 (1.97%), Buddhists 2 (1.32%), Sikh 1 (0.66%), and 3 (1.97%) preferred not to answer this question. The other religions accounted for 9 (5.92%), as described by the participants these were Heathen, Church of Scotland, Spiritual, Wiccan faith, and Alevi.

The sexual orientation of most participants was heterosexual 113 (74.34%). The sample included a diverse group of people with variable sexual orientations, 10 (6.58%) were homosexual, 12 (7.89%) bisexual, and 8 (5.26%) other orientation. However, 9 (5.92%) preferred not to answer this question.

At the time of data collection, most participants 128 (84.21%) were living in England and those living across the 42 counties are detailed in Table 5. The sample also included participants from other parts of the United Kingdom, 10 (6.58%) lived in Wales, 9 (5.92%) in Scotland, and 5 (3.29%) in Northern Ireland.

Table 5. *The regions where participants were living in the UK at the time of data collection*

Area/County	#	Area/County	#	Area/County	#
London	15	Cambridgeshire	3	North Yorkshire	1
Bedfordshire	11	Essex	3	Nottinghamshire	1
West Midlands	6	South Yorkshire	3	Somerset	1
Durham	5	Yorkshire	3	Suffolk	1
Norfolk	5	Berkshire	2	Shropshire	1
West Yorkshire	5	Devon	2	Telford	1
Hertfordshire	4	Leicestershire	2	Reading	1
Gloucestershire	4	Middlesex	2	West Sussex	1
Kent	4	Northumberland	2	Wiltshire	1
Lancashire	4	Staffordshire	2	Worcestershire	1
Lincolnshire	4	Brent	1	Non-specified	2
Manchester	4	Birmingham	1	England-Total	128
Northamptonshire	4	Bristol	1	Wales	10
Surrey	4	Derbyshire	1	Scotland	9
Buckinghamshire	3	Dorset	1	Northern Island	5
Cheshire	3	East Sussex	1	**Total**	152

The employment status of participants varied; 42 (27.63%) were full time employed, 42 (27.63%) students, 22 (21.71%) unemployed, 12 (8.55%) part-time employed, 11 (7.24%) self-employed, and 11 (7.24%) were retired. The participants were mainly professionals 41 (26.97%),

largely healthcare professionals, social workers, teachers, lecturers, consultants, and journalists. The rest of the sample included 12 (7.89%) service and sales workers, 9 (5.92%) clerical support workers, 8 (5.26%) managers, 6 (3.95%) technicians or associate professionals, 2 (1.3%) craft or related trade workers, 1 (0.66%) skilled agricultural or fishery workers, and 1 (0.66%) plant or machine operators. The remaining 72 (47.37%) participants had other non-stated occupations or were unemployed as explained in the previous question on employment status.

4.2.1.1 Self-reported disability

A total of 102 (67.11%) participants considered themselves as having a disability, 44 (28.95%) answered 'no' to the question on self-reported disability, while 6 (3.9.5%) did not want to specify disability status. Self-reported disability is illustrated in Figure 7.

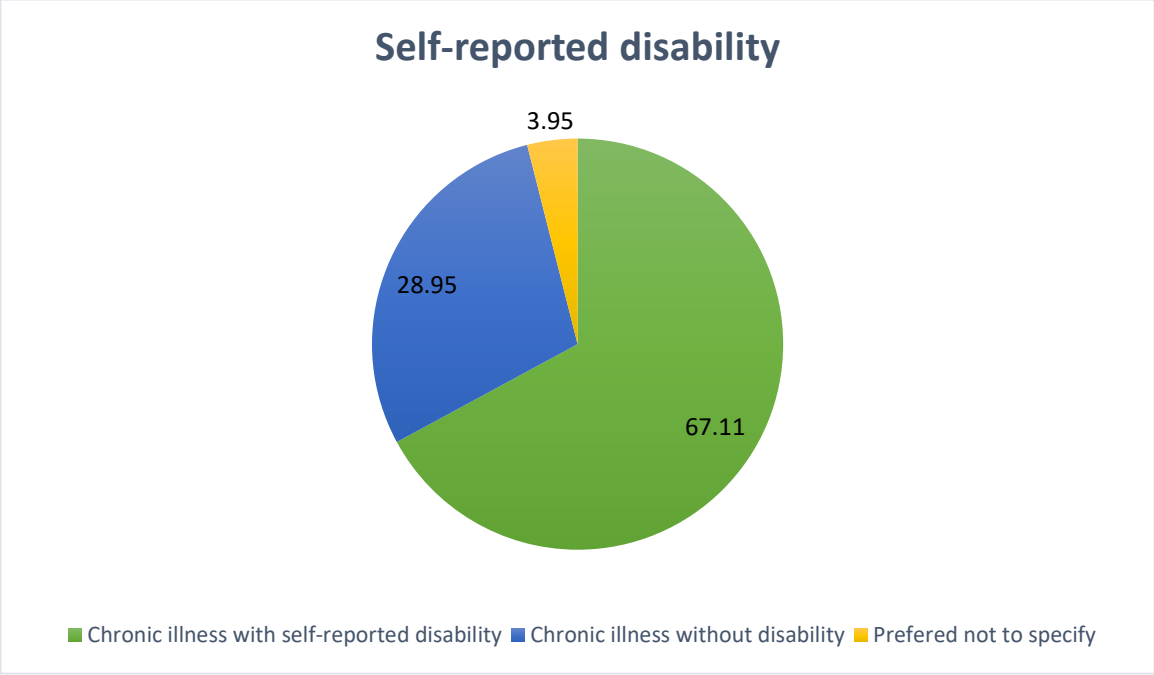

***Figure 7**. Self-reported disability in the sample (n = 152)*

4.2.2 The experience of having a long-term condition

The participants had a wide range of diverse health conditions, with most having multiple co-morbidities. Hence, a total of 340 health conditions was collectively reported as detailed in Table 6. The table provides the overall number of endorsements or entries by participants for each condition, then the next two columns provide the percentage of the category among all reported conditions (n = 340) and among all participants (n = 152).

Chronic lower respiratory diseases were highly reported, reaching a percentage of 15.59% of all conditions and 34.87% of participants. The most frequent health condition was asthma, which was endorsed by 45 participants, affecting 29.61% of the 152 participants and comprising 13.24% of all reported conditions. Other respiratory conditions were COPD and lung disease.

The second category was endocrine and metabolic diseases, in which diabetes mellitus affected the majority of participants. Diabetes affected 17.77% of participants, comprising 7.94% of reported conditions, with type 1 diabetes being more common than type 2 diabetes. Thyroid diseases were reported by 18 participants, while Wilson disease was reported by one patient.

Mental and behavioural disorders were the third most frequent, of which the most common conditions were anxiety, OCD and depression reported by 11, 11 and 9 participants respectively. This category included four participants having autism spectrum disorder and three with Asperger's syndrome. Diseases of the skin, eczema and psoriasis, were highly reported by 40 participants, and 11.76% among other conditions.

A wide spectrum of nervous system diseases was reported, comprising 11.18% of reported conditions, with the most frequent being multiple sclerosis (MS) and myalgic encephalomyelitis (ME), both affecting nine participants, followed by epilepsy, which was reported by seven

participants. Other conditions reported were primary headaches such as a migraine and cluster headaches, motor and sensory disorders.

Diseases of the musculoskeletal system were reported by 23.68% of participants. Rheumatoid arthritis (RA) and fibromyalgia were the most common conditions affecting the musculoskeletal system. However, a diverse range of connective tissue disorders was also reported such as hypermobility syndrome, gout, and scoliosis.

Diseases of the digestive system were also stated. Non-infective inflammatory bowel diseases (IBD) including Crohn's disease and ulcerative colitis were reported by 19 participants, affecting 12.50% of the sample. Participants also had irritable bowel syndrome (IBS), intestinal and gallbladder diseases.

Other less common, but no less debilitating conditions were also reported, such as conditions involving the genitourinary system (15 participants), and circulatory system disorders (13 participants). Congenital malformations and chromosomal abnormalities were also reported, in which Ehlers Danlos Syndrome (EHS) was the highest, affecting eight participants. Neoplasms, visual impairments, hearing impairments, and injuries were also present in the sample as broken down in Table 6.

***Table 6**. The category, number, and frequency of chronic conditions presented as a percentage among all reported conditions and among all participants*

Category	Number of endorsements or entries	% among all reported conditions (n=340)	% among participants (n=152)
Chronic lower respiratory diseases	**53**	**15.59%**	**34.87%**
Asthma	45		
Chronic obstructive pulmonary disease (COPD)	7		
Lung disease	1		
Endocrine, nutritional and metabolic diseases	**46**	**13.53%**	**30.26%**
Diabetes Mellitus	27 *Type I: 17 *Type II: 10		
Thyroid disease	18		
Wilson disease	1		
Mental and behavioural disorders	**46 (13.53%)**	**13.53%**	**30.26%**
Generalised anxiety disorder (GAD)	11		
Obsessive compulsive disorder (OCD)	11		
Depression	9		
Unspecified mental health condition	5		
Autism Spectrum Disorder	4		
Asperger's Syndrome	3		
Post-traumatic stress disorder (PTSD)	2		
Bipolar affective disorder	1		
Diseases of the skin and subcutaneous tissue	**40**	**11.76%**	**26.32%**
Eczema	26		

Psoriasis	14		
Diseases of the nervous system	**38 (11.18%)**	**11.18%**	**25.00%**
Multiple Sclerosis	9		
Myalgic encephalomyelitis (ME)	9		
Epilepsy	7		
Cerebral palsy	2		
Migraine headache	2		
Cluster headache	1		
Complex regional pain syndrome	1		
Balance disorders	1		
Charcot Marie Tooth	1		
Dysphasia/Dysphagia	1		
Essential tremor	1		
Narcolepsy	1		
Restless leg syndrome	1		
Nerve damage	1		
Diseases of the musculoskeletal system and connective tissue	**36 (10.59%)**	**10.59%**	**23.68%**
Rheumatoid arthritis	8		
Fibromyalgia	6		
Unspecified arthropathy	6		
Hypermobility syndrome	4		
Scoliosis	2		
Ankle-foot arthrosis	1		
Gout	1		
Failed back syndrome	1		
Soft tissue rheumatism	1		
Chronic tendinitis	1		

Spondylitis	1		
Osteoporosis	1		
Chronic coccydynia	1		
Wrist dissociation	1		
Foot disorder	1		
Diseases of the digestive system	**24**	**7.06%**	**15.79%**
Inflammatory bowel diseases (Crohn's and colitis)	19		
Irritable bowel syndrome (IBS)	3		
Intestinal cystitis	1		
Gallbladder disease	1		
Diseases of the genitourinary system	**15**	**4.41%**	**9.87%**
Chronic renal disease	6		
Polycystic ovarian syndrome (PCO)	3		
Urinary incontinence	2		
Bladder disorders	1		
Menstrual disorders	1		
Endometriosis	1		
Prostatic disorders	1		
Diseases of the circulatory system	**13**	**3.82%**	**8.55%**
Heart disease	6		
Postural orthostatic tachycardia	3		
Raynaud's syndrome	2		
Hypertension	1		
Vascular disorders	1		
Congenital malformations, deformations and chromosomal abnormalities	**10 (2.94%)**	**2.94%**	**5.58%**
Ehlers Danlos Syndrome	8		
Spina bifida	2		

Malignant neoplasm	**9**	**2.65%**	**5.92%**
Cancer	8		
Post-chemotherapy complications	1		
Disorders of the ear and mastoid process	**4**	**1.18%**	**2.63%**
Impaired hearing/deafness	3		
Tinnitus	1		
Diseases of the eye and adnexa	**3**	**0.88%**	**1.97%**
Retinopathy	1		
Impaired vision	1		
Corneal diseases	1		
Injuries and consequences of external causes	**3**	**0.88%**	**1.97%**
Spinal injury	2		
Lower leg amputation	1		
Total	**340**		

The frequency of multiple conditions reported by the participants as described above does not necessarily reflect their impact upon individuals. Hence, the participants were asked about the condition that affected them most. In this case, the top conditions were diabetes 23 (15.13%), psoriasis 14 (9.21%), EDS 10 (6.58%), ME 7 (4.61%), anxiety 7 (4.61%) and depression 7 (4.61%). The conditions that affected the participants most are detailed in Table 7. To reflect the impact on self-management, the remaining responses in this section correspond to the chronic conditions reported here as stated by the participants.

***Table 7**. The frequency of reported conditions by the participants when asked about the condition that affected them most (n = 152)*

Category	Count and percentage among participants n(%)
Chronic lower respiratory diseases	**6**
Asthma	6 (3.94%)
Endocrine, nutritional and metabolic diseases	**26**
Diabetes Mellitus	23 (15.13%)
Thyroid disease	3 (1.97%)
Mental and behavioural disorders	**27**
Generalised Anxiety Disorder (GAD)	7 (4.61%)
Depression	7 (4.61%)
Unspecified mental health condition	5 (3.29%)
Autism Spectrum Disorder	2 (1.32%)
Asperger's Syndrome	3 (1.97%)
Post-Traumatic Stress Disorder (PTSD)	2 (1.32%)
Bipolar Affective disorder	1 (0.66%)
Diseases of the nervous system	**23**
Multiple Sclerosis (MS)	5 (3.29%)
Myalgic encephalomyelitis (ME)	7 (4.61%)
Epilepsy	4 (2.63%)
Cerebral palsy	1 (0.66%)
Migraine headache	2 (1.32%)
Cluster headache	1 (0.66%)
Charcot Marie Tooth	1 (0.66%)
Narcolepsy	1 (0.66%)
Restless leg syndrome	1 (0.66%)
Diseases of the musculoskeletal system and connective tissue	**17**
Rheumatoid arthritis	2 (1.32%)
Fibromyalgia	6 (3.95%)

Unspecified arthropathy	4 (2.63%)
Hypermobility syndrome	3 (1.97%)
Ankle-foot arthrosis	1 (0.66%)
Failed back syndrome	1 (0.66%)
Diseases of the skin and subcutaneous tissue	**18**
Eczema/acne	4 (2.63%)
Psoriasis	14 (9.21%)
Diseases of the digestive system	**8**
Inflammatory Bowel Diseases (Crohn's and colitis)	6 (3.95%)
Irritable Bowel Syndrome (IBS)	1 (0.66%)
Gallbladder disease	1 (0.66%)
Diseases of the genitourinary system	**8**
Chronic renal disease	3 (1.97%)
Polycystic Ovarian Syndrome (PCO)	1 (0.66%)
Bladder disorders	1 (0.66%)
Menstrual disorders	1 (0.66%)
Endometriosis	2 (1.32%)
Diseases of the circulatory system	**4**
Heart disease	2 (1.32%)
Vascular disorders	2 (1.32%)
Congenital malformations, deformations and chromosomal abnormalities	**11**
Ehlers Danlos Syndrome	10
Spina bifida	1 (0.66%)
Malignant neoplasm	**2**
Cancer	2 (1.32%)
Disorders of the ear and mastoid process	**1**
Impaired hearing/deafness	1 (0.66%)
Injuries and consequences of external causes	**1**
Lower leg amputation	1 (0.66%)
Total of reported conditions	**152 (100%)**

With regards to the diagnosis process and its disruptive impact on the patients, most participants 136 (89.47%) were diagnosed with one or more long-term conditions by a doctor in the UK, 8 (5.26%) were diagnosed by a doctor abroad, 3 (1.97%) had self or family diagnosis, and 4 (2.63%) were diagnosed by others. The last category included other healthcare professionals such as neurologists, psychologists and/or social services. Lastly, 1 (0.66%) did not remember who diagnosed him/her. The participants were diagnosed as early as birth or one year old to aged 61 years.

The participants recalled their reactions to their diagnosis of the chronic condition, with the majority 108 (71.05%) reported feeling fear. However, the degree of fear varied between slight to extreme fear and distress as detailed in Table 8. Other participants (11.84%) had no fear, and 17.11% did not know or remember their first reaction to diagnosis.

***Table 8**. Participants' reaction to the diagnosis*

Reaction to diagnosis	n(%)
Had no fear or distress	18(11.84%)
Slight fear/distress	43(28.29%)
Moderate fear/distress	41(26.97%)
Extreme fear/distress	24(15.79%)
I don't know	26(17.11%)
Total	152(100%)

The reported duration associated with each chronic condition varied, ranging from months to more than 20 years. A total of 283 conditions were reported with durations. Due to having multiple comorbidities, the provided percentage corresponds to the number of conditions and their durations and not the participants. The most common duration was the longest; 91 (32.16%)

participants had the chronic condition for more than 20 years. The remaining durations were as follows: 23 (8.13%) conditions were diagnosed for less than one year, 25 (8.83%) for 1 to 2 years, 36 (12.72%) for 3 to 5 years, 34 (12.01%) for 5 to 10 years, and 74 (26.15%) for 10 to 20 years.

4.2.2.1 The existing self-management plan

The management plan of most participants involved multiple aspects, hence, 152 participants shared a total of 999 endorsements of elements of their management plans, as shown in Table 9. The most common element of health management was related to lifestyle changes including avoiding triggers that exacerbate illness (61.18%), healthy eating (50.66%), avoiding excessive drinking (43.42%), and physical activity (41.45%). Pharmacological treatment was also reported by most participants, including regular medications (66.45%) and prescription medications (50%).

Patients' follow up was mainly with specialists (51.97%) and GPs (44.74%), while monitoring was via self-monitoring (32.24%) and laboratory tests (22.37%). Other management aspects not included in the list, but shared by the participants, were oxygen support, pain management, independent management without professionals' help, hypnotherapy, hearing aids, peak flow meter, meditation, specific diet, hygiene, hydration, pacing, and rest.

Table 9 *The participants' self-management plan for chronic conditions*

Answer	Number of endorsements or entries	% among participants (n=152)
Lifestyle changes		
Avoiding particular triggers that exacerbate your illness	93	61.18%
Healthy eating	77	50.66%
Avoiding excessive drinking	66	43.42%
Exercise/physical activity	63	41.45%
Avoiding smoking	51	33.55%
Avoiding particular type of food	47	30.92%
Other lifestyle changes	38	25.00%
Pharmacological		
Regular medications	101	66.45%
Medications on need (prescription)	76	50.00%
Medications on need (Over The Counter)	27	17.76%
Follow up		
Regular follow up with specialist	79	51.97%
Regular follow up with GP	68	44.74%
Regular follow up with other health care professionals	44	28.95%
Physiotherapy	21	13.82%
Counselling sessions	29	19.08%
Monitoring		
Self-monitoring at home (example: blood sugar)	49	32.24%
Regular lab tests	34	22.37%
Other		
Alternative/complimentary medicine (such as herbal treatment, aromatherapy, acupuncture)	18	11.84%
Other management	18	11.84%
Total	**999**	**-**

4.2.3 Cyber-victimisation experience

One of the main objectives of this study was to scope cyber-victimisation among people with long-term conditions. This experience was found to be prevalent, almost one in every two participants was victimised, with a total of 69 (45.39%) participants responding 'yes' to the question 'Have you ever experienced that someone unwantedly contacted you repeatedly (more than once) via the Internet such as email, chatroom, online forum, social network, mobile phone message, or other electronic means and used it to harass, insult, embarrass, or spread lies about you?' The term 'victim' will be used from this point onward to refer to this group of participants. This result is illustrated in Figure 8. When the participants were asked about self-reported victim status, 53 (34.87%) considered themselves 'victims' of cyber-victimisation, 89 (58.55%) responded no to this question, while 10 (6.58%) did not know their self-reported victim status.

Figure 8. *The prevalence of cyber-victimisation in response to the question listing cyber-victimisation criteria (n = 152)*

The majority of victims 60 (88.24%) reported experiencing fear and distress secondary to cyber-victimisation, ranging from experiencing extreme fear and distress by 22 (32.35%) participants, to moderate fear by 24 (35.29%), and slight fear by 14 (20.59%) victims. Only eight participants stated having no fear secondary to the cyber-victimisation experience. This is summarised in Table 10.

Table 10. *Victims' reaction to their cyber-victimisation experience*

Victim's reaction to cyber-victimisation	n(%)
No fear	8(11.76%)
Slight fear	14(20.59%)
Moderate fear	24(35.29%)
Extreme fear	22(32.35%)
Total	**68(100%)**

The duration of the victimisation was more than a year in 25 (36.76%) cases, from three months to one year in 15 (22.06%) cases, as shown in Table 11. Additionally, the harassment was ongoing in 17 (25.00%) cases, and 12 (17.65%) victims were not sure whether the campaign had ended.

Table 11*.The duration of the cyber-victimisation experience as reported by the victims*

The duration of harassment	n(%)
Less than 2 weeks	9(13.24%)
From 2 weeks to 4 weeks	11(16.18%)
From 5 weeks to 2 months	8(11.76%)
From 3 months to one year	15(22.06%)
More than a year	25(36.76%)
Total	**68(100%)**

The most common means to contact the victims was Facebook, which was reported by 43 (63.24%) participants, followed by personal email or text messaging, each accounting for 27(39.71%) of participants. Phone calls were reported by 26 (38.24%) victims. Other means of contact included websites such as eBay, chatrooms, spam subscriptions, or hacking into friends' accounts. It is of note that nine victims (13.24%) were victimised in online health forums. The frequency of contact varied between participants, between once or more per day to less than once a month. Most victims 67 (98.53%) were contacted once or more per day by their harassers. However, each means of contact had different frequencies and durations as shown in Table 12.

***Table 12**. The means used to contact the victim with frequencies and duration (n = 68)*

Mean of contact	Once or more per day	More than three times per week	Once per week	Once per month	Less than once a month	Total
Facebook	13	14	4	7	5	43 (63.24%)
Personal email	9	7	4	4	3	27 (39.71%)
Text messaging (examples: SMS, Whatsapp)	11	6	1	6	3	27 (39.71)
Phone calls	6	6	5	4	5	26 (38.24%)
Other	8	6	3	2	6	25 (36.76%)
Twitter	9	2	4	3	2	20 (29.41%)
Blogs	5	1	2	1	4	13 (19.18%)
Online health forums	3	2	1	2	1	9 (13.24%)
Work email	2	1	0	2	0	5 (7.35%)
YouTube	0	0	1	2	1	4 (5.88%)
Instagram	1	0	0	1	1	3 (4.41%)
Total	**67** (98.53%)	**45** (66.18%)	**25** (36.76%)	**34** (50.00%)	**31** (45.59%)	

With regards to the harasser's relationship to the victims, from the victim's point of view, most harassers (29.41%) were strangers, 14 (20.59%) were identified as an acquaintance, 9 (13.24%) were victimised by ex-partners, however, 10 (14.71%) victims were not sure about the identity of their harassers as shown in Table 13. Additionally, 16 (23.53%) victims specified other categories such as neighbours, ex-partner's partner, or fellow members of online support groups.

Table 13. *Harassers' relationship with the victims*

Harasser's relation to the victims	**Frequency**
Stranger	20 (29.41%)
Other, please specify	16 (23.53%)
Acquaintance	14 (20.59%)
Unknown (I am not sure about the identity of my harasser)	10 (14.71%)
Ex-partner	9 (13.24%)
Family	6 (8.82%)
Work colleague	5 (7.35%)
Close friend	4 (5.88%)
Professional contact	0 (0.00%)
Total	**68 (100%)**

When the victims were asked whether they perceived any relationship between having a long-term condition and being cyber-victimised, 22 (41.51%) out of 53 victims perceived that the targeting was related to their conditions as shown in Figure 9. The victims were provided with a space to explain their answers as covered in the next section.

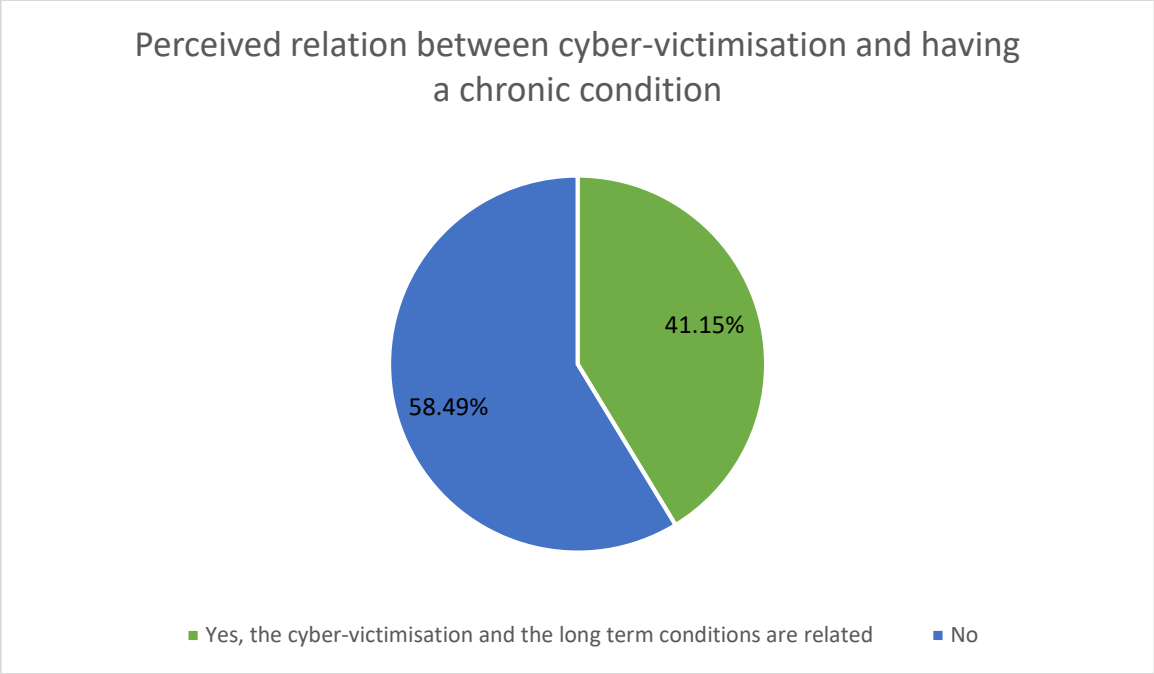

***Figure 9**. The perceived relationship between having a chronic condition and being victimised online*

4.2.4 The impact of cyber-victimisation

One of the objectives of this study was to scope the impact of cyber-victimisation on people with long-term conditions. From the victim's perspective, most victims 33 (61.11%) reported that the experience of cyber-victimisation had affected their self-management of chronic conditions.

The victims who responded 'yes' were given their personalised management plan as they shared individually, and were asked to endorse the parts of the plan that were affected. In total, 32 victims shared these specific changes, with the most common changes related to lifestyle, followed by taking medications, then follow up. The categories are presented as frequencies in Figure 10.

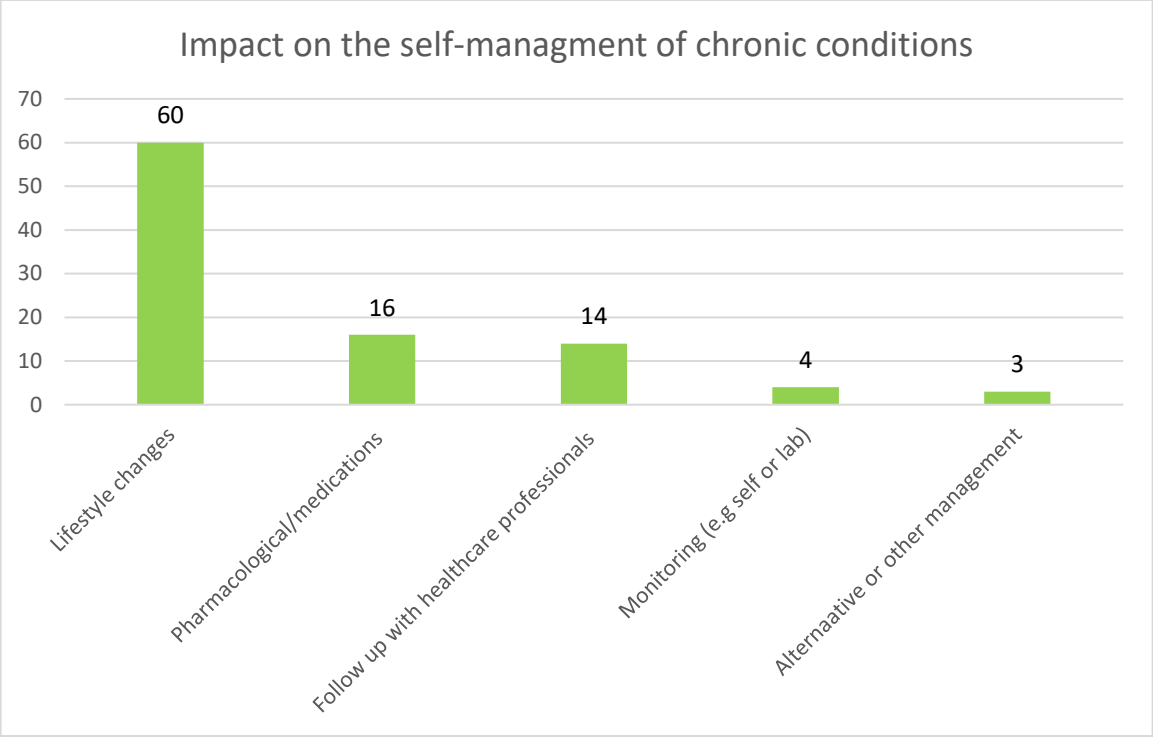

***Figure 10**. The perceived impact of cyber-victimisation on The self-management of chronic conditions presented as frequency*

A further breakdown of the changes imposed by cyber-victimisation on the self-management of chronic conditions showed that 19 (59.38%) victims described changes in avoiding triggers that exacerbate illness, 12 (37.50%) made changes to their diet, and 10 (31.25%) avoided exercise and physical activity. Other lifestyle changes and avoiding excessive drinking were also reported. In terms of pharmacological treatments, regular medications were mostly affected, as reported by 9 (28.13%) participants. Follow up with healthcare professionals was also impacted, especially with GPs and counsellors, both of which were reported by 5 (15.63%) victims. However, other less common elements were affected in the management plan, reported by four or fewer participants, yet no less devastating, as detailed in Table 14.

Table 14. Victims' responses to what specific aspects of the self-management of chronic conditions was affected (n = 32)

Affected aspects of The self-management of chronic conditions	Frequency of endorsements	Percentage of victims (n=32)
Lifestyle changes	**60**	**-**
Avoiding particular triggers that exacerbate your illness	19	59.38%
Healthy eating	12	37.50%
Avoiding excessive drinking	5	15.63%
Exercise/physical activity	10	31.25%
Avoiding smoking	4	12.50%
Avoiding particular type of food	4	12.50%
Other lifestyle changes	6	18.75%
Pharmacological	**16**	**-**
Regular medications	9	28.13%
Medications on need (prescription)	4	12.50%
Medications on need (over The Counter)	3	9.38%
Follow up	**14**	
Regular follow up with specialist	2	6.25%
Regular follow up with GP	5	15.63%
Regular follow up with other health care professionals	2	6.25%
Physiotherapy	0	0.00%
Counselling sessions	5	15.63%
Monitoring	**5**	**-**
Self-monitoring at home (example: blood sugar)	3	9.38%
Regular lab tests	2	6.25%
Other	**3**	
Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture)	**3**	9.38%
Other management	0	11.84%
Total	**93**	**-**

To confirm these results, 32 victims responded to the question providing them with a number of statements to endorse, which were ranked on a 5-point Likert scale ranging from always to never. Their responses confirmed the impact in the previous table and reflected multi-level effects on health management as illustrated in Figure 11. Some participants (n = 26) added other effects,

which included disruptions to social relationships, general disruption to health or specific to health conditions, or suicidal attempts. Exercise was most commonly affected due to being scared or too tired, followed by appetite issues and a general feeling of being unwell.

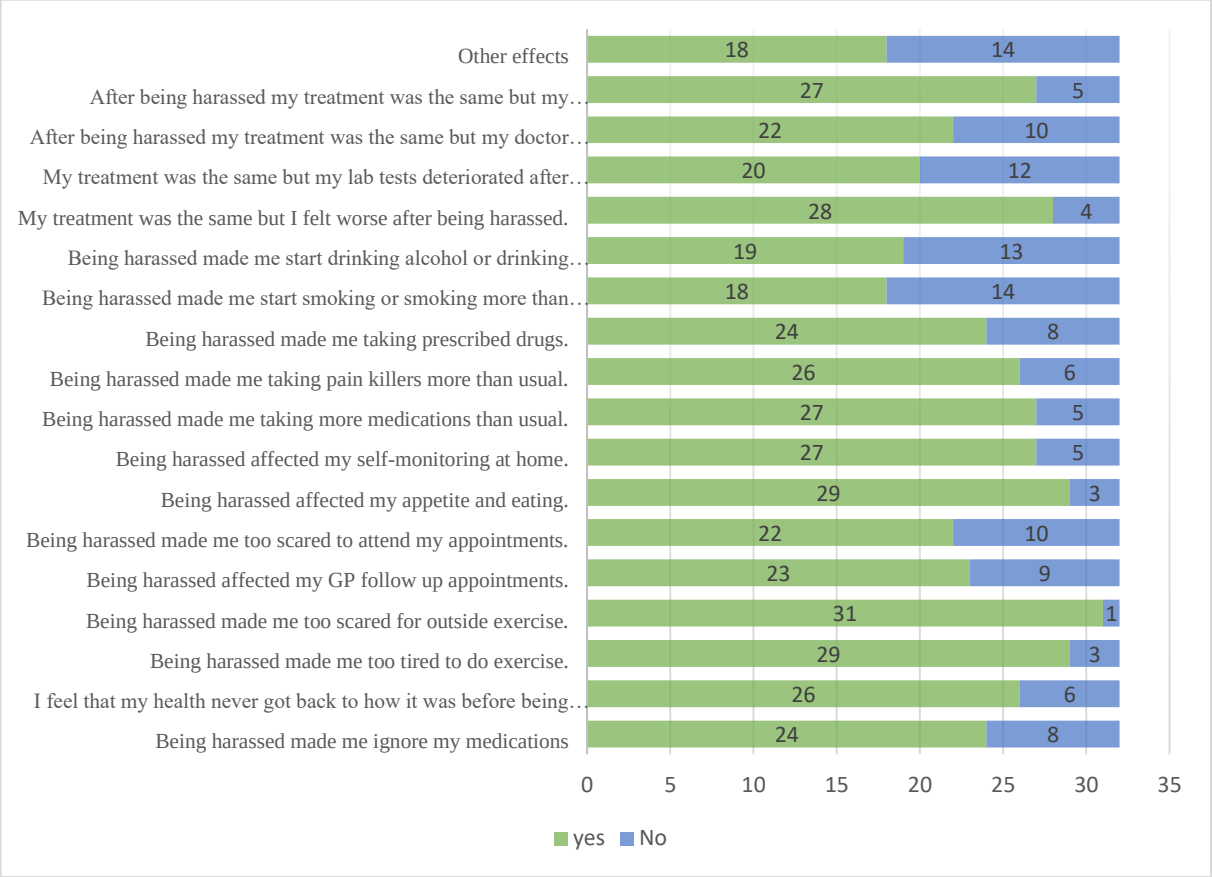

Figure 11. *Victims' endorsements to a set of statements describing the impact of cyber-victimisation on their management plans*

The responses to the statements on the 5-point Likert scale are further detailed in Figure 12, where the numbers indicate the number of endorsements by victims to each statement and how often it happened. As illustrated, exercise and a general feeling of having poor health were given more 'always' points on the scale.

***Figure 12**. Impact on self-management of conditions presented as statements endorsed by participants (n = 32)*

4.2.4.1 The impact of cyber-victimisation on each condition

The results reported above were further cross-checked to identify the impact of cyber-victimisation on each chronic condition as summarised in Table 15. This is of importance because of the specific differences between conditions. For example, healthy eating was commonly affected, however, its complications are different between diabetes and depression.

***Table 15**. The impact of cyber-victimisation on the management plan of each reported condition*

Category	Reported impact
Endocrine, nutritional and metabolic diseases	
Diabetes Mellitus	• Healthy eating** • Avoiding particular triggers that exacerbate your illness-** • Monitoring at home (example: blood sugar) • Avoiding particular type of food. • Avoiding smoking • Avoiding excessive drinking, • Exercise/physical activity • Regular medications
Mental and behavioural disorders	
Generalised anxiety disorder (GAD)	• Other lifestyle changes, such as: relaxing • Avoiding particular triggers that exacerbate your illness • Exercise/physical activity
Depression	• Avoiding smoking • Healthy eating** • Regular follow up with GP • Counselling sessions • Avoiding particular triggers that exacerbate your illness • Regular medications • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture) • Avoiding excessive drinking
Unspecified mental health condition	• Healthy eating • Counselling sessions • Avoiding particular triggers that exacerbate your illness • Avoiding smoking • Exercise/physical activity

Asperger's Syndrome	• Avoiding particular triggers that exacerbate your illness
Post-traumatic stress disorder (PTSD)	• Medications on need (Over The Counter) • Regular follow up with specialist • Regular follow up with other healthcare professionals • Counselling sessions • Avoiding particular triggers that exacerbate your illness • Other lifestyle changes • Regular medications
Bipolar affective disorder	• Regular follow up with other healthcare professionals • Avoiding particular triggers that exacerbate your illness • Avoiding excessive drinking
Diseases of the nervous system	
Myalgic encephalomyelitis (ME)	• Avoiding particular triggers that exacerbate your illness • Other lifestyle changes • Avoiding excessive drinking
Epilepsy	• Healthy eating • Avoiding particular triggers that exacerbate your illness • Medications on need (prescription)
Migraine headache	Healthy eating
Narcolepsy	• Healthy eating • Self-monitoring at home (example: blood sugar) • Avoiding a particular type of food • Avoiding particular triggers that exacerbate your illness • Avoiding excessive drinking • Exercise/physical activity • Regular medications
Restless leg syndrome	• Regular follow up with GP • Avoiding particular triggers that exacerbate your illness • Regular medications

Diseases of the musculoskeletal system and connective tissue	
Rheumatoid arthritis	• Healthy eating • Medications on need (Over The Counter) • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture) • Other management • Avoiding a particular type of food • Avoiding particular triggers that exacerbate your illness • Exercise/physical activity • Other lifestyle changes
Fibromyalgia	Healthy eating** • Self-monitoring at home (example: blood sugar) • Other management, • Avoiding particular triggers that exacerbate your illness • Other lifestyle changes • Regular medications** • Medications on need (prescription) • Regular follow up with GP • Avoiding a particular type of food • Medications on need (prescription)
Diseases of the skin and subcutaneous tissue	
Eczema/acne	• Healthy eating • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture) • Avoiding excessive drinking
Psoriasis	• Exercise/physical activity**
Diseases of the genitourinary system	
Menstrual disorders	• Healthy eating

	• Regular follow up with specialist • Counselling sessions • Avoiding particular triggers that exacerbate your illness • Avoiding smoking • Exercise/physical activity • Regular medications
Diseases of the circulatory system	
Heart disease	• Regular follow up with GP** • Avoiding particular triggers that exacerbate your illness** • Regular medications
Congenital malformations, deformations and chromosomal abnormalities	
Ehlers Danlos Syndrome	• Medications on need (Over The Counter) • Medications on need (prescription) • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture) • Exercise/physical activity** • Counselling sessions • Avoiding particular triggers that exacerbate your illness** • Other lifestyle changes

**Indicates more than one endorsement

4 5.2.4.2 The self-management efficacy scale of chronic conditions

To measure the perceived impact, Self-Efficacy for Managing Chronic Disease 6-item Scale was calculated for 55 victims. The standardised scale was part of the survey as explained in section 3.3.2. People who experienced cyber-victimisation were asked to fill the same scale

considering two different occasions, one occasion was to reflect on their self-management before the cyber-victimisation experience, and the second copy of the same scale was filled considering their management after experiencing cyber-victimisation. The scale was calculated for each victim before and after the cyber-victimisation experience, it was negative in 38 responses, positive in 7 cases, and zero in 10 cases. Hence, a negative difference in scale in Table 16 indicates a perceived negative impact of cyber-victimisation on the self-management of chronic conditions. Hence, most victims 38 (69.09%) perceived negative changes to their self-management, irrespective of their responses to the previous question. Table 16 summarises the scale for 55 participants.

Table 16. *Perceived self-management of chronic conditions on a self-efficacy scale for each victim, before and after victimisation (n = 55)*

#	Self-management scale **before** cyber-victimisation, per each participant, out of 10	Self-management scale **after** cyber-victimisation per each participant, out of 10	Difference in scale
1	2.00	1.50	-0.50
2	7.00	0.00	-7.00
3	10.00	10.00	0.00
4	2.00	1.67	-0.33
5	7.33	3.67	-3.67
6	6.17	1.50	-4.67
7	9.17	9.17	0.00
8	8.83	8.50	-0.33
9	10.00	0.00	-10.00
10	10.00	10.00	0.00
11	1.00	0.83	-0.167
12	5.00	0.00	-5.00
13	1.67	1.67	0.00
14	9.67	5.67	-4.00
15	0.67	0.50	-0.17
16	10.00	0.00	-10.00
17	9.33	10.00	0.67

18	8.33	8.00	-0.33
19	4.83	4.83	0.00
20	6.00	6.00	0.00
21	2.83	0.00	-2.83
22	0.00	0.00	0.00
23	8.17	8.17	0.00
24	8.67	6.00	-2.67
25	8.67	7.00	-1.67
26	9.00	2.33	-6.67
27	9.00	3.50	-5.50
28	5.17	0.17	-5.00
29	5.00	5.33	0.33
30	0.33	0.17	-0.17
31	9.50	2.00	-7.50
32	5.00	7.50	2.50
33	5.50	0.50	-5.00
34	7.83	0.00	-7.83
35	8.50	1.33	-7.17
36	3.67	2.50	-1.17
37	7.83	0.83	-7.0
38	7.00	4.17	-2.83
39	6.33	8.17	1.83
40	2.00	1.67	-0.33
41	5.67	5.67	0.00
42	6.17	3.00	-3.17
43	3.50	5.33	1.83
44	5.67	2.83	-2.83
45	4.50	8.67	4.17
46	4.00	3.17	-0.83
47	6.33	3.67	-2.67
48	8.33	6.33	-2.00
49	0.00	7.00	7.00
50	8.33	5.17	-3.17
51	7.00	4.67	-2.33
52	1.83	0.67	-1.17
53	7.33	3.33	-4.00
54	6.83	2.00	-4.83
55	2.00	2.00	0.00

4.2.5 Support

The victims sought formal and informal support to cope with the cyber-victimisation experience. Informal support was more common, mainly seeking help from family members and friends as detailed in Table 17. A total of 37 (71.15%) victims out of 52 respondents got support from their families. Of those, 14 (37.84%) rated family support very good, 10 (27.03%) rated it good, and 11 (29.73%) thought it was poor. Most victims also got support from their friends 40 (76.92%), which they rated as primarily very good 17 (42.50%) or poor 7 (17.50%).

Formal support was less common, with only 20 (40.00%) victims contacting victim support groups, and the majority of them 11 (55.00%) rated the support as poor. Twenty-two victims contacted healthcare professionals including mental health practitioners, social workers or GPs. However, 10 (45.45%) of them rated the support very good and 6 (27.27%) rated it poor. A total of 20 victims contacted the police, but most of them 13 (65%) considered the support as poor. Some victims 18 (36.73%) approached other channels such as employers, other charities, media, online support groups, website's admin, or solicitors. These other channels were generally rated poor by 6 (33.33%) participants and very good by another 6 (33.33%) victims.

***Table 17**. Informal and formal support sought by the victims and the perceived effectiveness of the support provided*

Support channel	Yes, approached this channel	Rating of support received				No, did not approach	Total respondents
		Poor	*Fair*	*Good*	*Very good*		
Family	**37(71.15%)**	11	2	10	14	**15 (28.85%)**	52
Friends	**40(76.92%)**	7	7	9	17	**12 (23.08%)**	52
Victim support groups	**20(40.00%)**	11	4	3	2	**30 (60.00%)**	50
Healthcare professional	**22(42.31%)**	6	4	2	10	**30 (60.00%)**	52
Police	**20(38.46%)**	13	1	3	3	**33 (36.26%)**	53
Other channels	**18(36.73%)**	6	2	4	6	**31 (63.27%)**	49

***** The percentages are based on the total number of respondents to each support channel***

When asked about their GPs, 13 victims out of 53 (24.53%) respondents to this question stated that they have spoken to their GPs about what they were going through, as illustrated in Figure 13. Of those, three victims rated the support poor, while five others rated it fair, two victims considered it was good and two victims thought it was very good support.

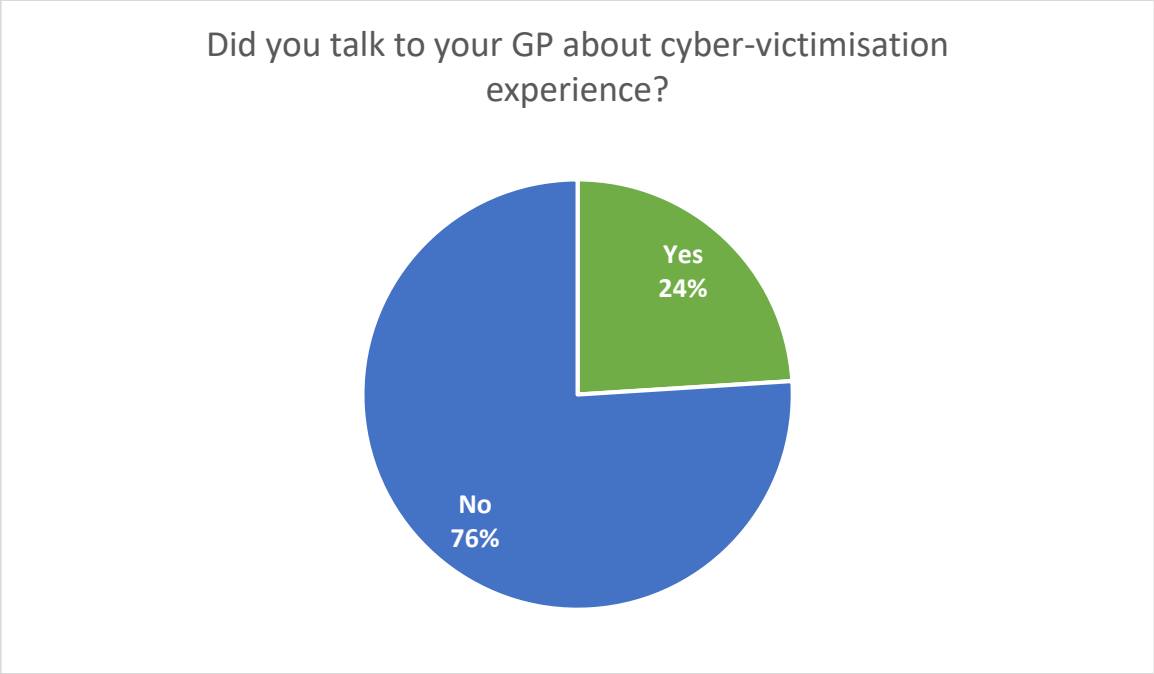

***Figure 13**. The percentage of victims who communicated the cyber-victimisation experience to their GPs*

4.2.6 Cross-tabulation and comparisons

4.2.6.1 Characteristics of victims

The results were filtered to identify the responses reported by the victims only for later comparison to the whole sample in Table 22 and further in the discussion (section 5.7). Table 18 provides the age distribution only for the victims, the distribution covers all age groups and the most common category was aged 30-39 years.

Table 18. The age groups of victims (n = 69)

Age group of victims	n(%)
18 -19	6(8.70%)
20-29	17(24.64%)
30-39	19(27.54%)
40-49	14(20.29%)
50-59	8(11.59%)
60+	5(7.25%)
Total	69(100%)

The reported conditions by the victims are shown in Table 19, with the most common being respiratory, mental, endocrine, neurological and musculoskeletal conditions. However, the conditions that affected them most are summarised in Table 20, in which diabetes was the most common, followed by depression and EDS, fibromyalgia and anxiety. Further tabulations will be presented in the next sub-section.

***Table 19**. The long-term conditions reported by the victims*

Category	The number of endorsements or entries by the victims	The frequency of the condition in relation to all of the conditions reported by the victims (n=155)	The frequency of the condition among the victims only (n=69)
Chronic lower respiratory diseases	**28**	**18.06%**	**40.58%**
Asthma	23		
Chronic obstructive pulmonary disease (COPD)	5		
Endocrine, nutritional and metabolic diseases	**22**	**14.19%**	**31.88%**
Diabetes Mellitus	13 *Type I: 7 *Type II: 6		
Thyroid disease	8		
Wilson disease	1		
Mental and behavioural disorders	**24**	**15.48%**	**34.78%**
Generalised anxiety disorder (GAD)	6		
Obsessive compulsive disorder (OCD)	2		
Depression	10		
Unspecified mental health condition	3		
Asperger's Syndrome	1		
Post-traumatic stress disorder (PTSD)	1		
Bipolar affective disorder	1		
Diseases of the skin and subcutaneous tissue	**6**	**3.87%**	**8.70%**
Eczema	1		
Psoriasis	5		
Diseases of the nervous system	**23**	**14.84%**	**33.33%**
Multiple Sclerosis (MS)	4		
Myalgic encephalomyelitis (ME)	6		
Epilepsy	4		
Cerebral palsy	1		
Migraine headache	2		
Charcot Marie Tooth	1		
Essential tremor	1		
Narcolepsy	1		
Restless leg syndrome	2		
Nerve damage	1		

Diseases of the musculoskeletal system and connective tissue	**16**	**10.32%**	**23.19%**
Rheumatoid arthritis	4		
Fibromyalgia	5		
Hypermobility syndrome	1		
Failed back syndrome	1		
Chronic tendinitis	1		
Spondylitis	1		
Osteoporosis	1		
Chronic coccydynia	1		
Wrist dissociation	1		
Diseases of the digestive system	**13**	**88.39%**	**18.84%**
Inflammatory bowel diseases (Crohn's and colitis)	8		
Irritable bowel syndrome (IBS)	3		
Intestinal cystitis	1		
Gallbladder disease	1		
Diseases of the genitourinary system	**3**	**1.94%**	**4.35%**
Chronic renal disease	1		
Urinary incontinence	1		
Menstrual disorders	1		
Diseases of the circulatory system	**8**	**5.16%**	**11.59%**
Heart disease	4		
Postural orthostatic tachycardia	2		
Raynaud's syndrome	2		
Congenital malformations, deformations and chromosomal abnormalities	**6**	**3.87%**	**8.70%**
Ehlers Danlos Syndrome	6		
Malignant neoplasm	**1**	**0.65%**	**1.45%**
Cancer	1		
Disorders of the ear and mastoid process	**1**	**0.65%**	**1.45%**
Impaired hearing/deafness	1		
Diseases of the eye and adnexa	**2**	**1.29%**	**2.90%**
Impaired vision	2		
Injuries and consequences of external causes	**2**	**1.29%**	**2.90%**
Spinal injury	1		
Lower leg amputation	1		
Total	**155**		

As shown in table 19, most of the victims had multiple co-morbidities across several physiological systems. However, when the victims were asked about the conditions that affected them most they endorsed diabetes mellitus, Anxiety, depression, fibromyalgia and Ehlers Danlos Syndrome. These conditions are highlighted in Table (20), and they indicate that the impact of living with a chronic condition reflects the personal experience rather than epidemiological statistics.

Table 20. *The conditions that affected the victims most.*

Category	Count and percentage among victims n(%)
Chronic lower respiratory diseases	
Asthma	4(5.60%)
Endocrine, nutritional and metabolic diseases	
Diabetes Mellitus	11(15.94%)
Thyroid disease	2(2.90%)
Mental and behavioural disorders	
Generalised Anxiety Disorder (GAD)	5(7.25%)
Depression	5(7.25%)
Unspecified mental health condition	3(4.35%)
Autism Spectrum Disorder	-
Asperger's Syndrome	1(1.45%)
Post-Traumatic Stress Disorder (PTSD)	1(1.45%)
Bipolar Affective disorder	1(1.45%)
Diseases of the nervous system	
Multiple Sclerosis (MS)	2(2.90%)
Myalgic encephalomyelitis (ME)	3(4.35%)
Epilepsy	2(2.90%)
Cerebral palsy	1(1.45%)
Migraine headache	2(2.90%)

Cluster headache	-
Charcot Marie Tooth	1(1.45%)
Narcolepsy	1(1.45%)
Restless leg syndrome	1(1.45%)
Diseases of the musculoskeletal system and connective tissue	
Rheumatoid arthritis	1(1.45%)
Fibromyalgia	5(7.25%)
Unspecified arthropathy	1(1.45%)
Hypermobility syndrome	-
Ankle-foot arthrosis	-
Failed back syndrome	1(1.45%)
Diseases of the skin and subcutaneous tissue	
Eczema/acne	1(1.45%)
Psoriasis	4(5.60%)
Diseases of the digestive system	
Inflammatory Bowel Diseases (Crohn's and colitis)	1(1.45%)
Irritable Bowel Syndrome (IBS)	-
Gallbladder disease	1(1.45%)
Diseases of the genitourinary system	
Chronic renal disease	-
Polycystic Ovarian Syndrome (PCO)	-
Bladder disorders	-
Menstrual disorders	1(1.45%)
Endometriosis	-
Diseases of the circulatory system	
Heart disease	2(2.90%)
Vascular disorders	-
Congenital malformations, deformations and chromosomal abnormalities	
Ehlers Danlos Syndrome	5(7.25%)
Spina bifida	-

Malignant neoplasm	
Cancer	-
Disorders of the ear and mastoid process	
Impaired hearing/deafness	-
Injuries and consequences of external causes	
Lower leg amputation	1(1.45%)
Total of reported conditions	69(100%)

* The highlighted conditions represent the conditions that affected the victims most from their perspective irrespective to their frequencies in the sample.

The reaction of the victims to the diagnosis of the conditions above is reported in Table 21. This is of importance to examine the level of disruption as discussed in section theory and will be further covered in section 5.10.2 in the discussion chapter.

Table 21. *The level of fear/distress among the participants who experienced victimisation when they were first diagnosed with the conditions reported above.*

Victims' reaction to diagnosis	**n(%)**
Had no fear or distress	5(7.25%)
Slight fear/distress	14(20.29%)
Moderate fear/distress	22(31.88%)
Extreme fear/distress	16(23.19%)
I don't know	12(17.39%)
Total	69(100%)

In order to find commonalities and differences between the whole sample, the victims, and the victims with self-reported disabilities, the characteristics of each of these groups were cross-tabulated and summarised in Table 22; these will be further discussed in the discussion (Chapter 6).

Table 22 *Comparison between the main characteristics of all participants, victims and victims with disabilities*

Characteristics	All participants with chronic conditions (n=152)	Victims (n=69)	Victims with disabilities (n=53)
Demographics			
Gender	Female 120(78.95%)	Female 56(81.16%)	Female 43 (81.13)
Ethnic background	White 131(86.18%)	White 61(88.41%)	White 48(90.57%)
Age	Range: 18-65 years Mean 34.74 (SD= 12.98)	Range: 18-63 years Mean 36.87 (SD= 12.65)	Range: 18-63 years Mean 37.96 (SD= 13.10)
Religion	No religion 74(48.68%)	No religion 38(55.07%)	No religion 8(52.83%)
Region	England 128(84.21%)	England 57(82.61%)	England 44(83.82%)
Employment status	42(27.63%) full time employed, 42(27.63%) students 22(21.71%) unemployed, 12(8.55%) part-time 11(7.24%) self-employed, 11(7.24%) retired	18(26.09%) full time employed, 15(21.74%) students 20(28.99%) unemployed, 5(7.25%) part-time 11(7.24%) self-employed, 4(5.80%) retired	10(18.87%) full time employed, 12(22.64%) students 19(35.85%) unemployed, 3(5.66%) part-time 5(9.43%) self-employed, 4(7.55%) retired
Professions	41(26.97%) professionals 12(7.89%) service/sales 9(5.92%) clerical support 8(5.26%) managers 6(3.95%) technicians/ associate professionals, 2(1.3%) craft/trade 1(0.66%) skilled agricultural or fishery 1(0.66%) plant/machine operators	17(24.64%) professionals 7(10.14%) service/sales 1(1.45%) clerical support 5(7.25%) managers 1(1.45%) technicians/ associate professionals, 0(0.00%) craft/trade 1(1.45%) skilled agricultural or fishery 1(1.45%) plant/machine operators	12(22.64%) professionals 4(7.55%) service/sales 1(1.89%) clerical support 2(3.77%) managers 1(1.89%) technicians/ associate professionals, 2(1.3%) craft/trade 1(1.89%) skilled agricultural or fishery 1(1.89%) plant/machine operators
Sexual orientation	Straight 113(74.34%) gay/lesbian 10(6.58%) bisexual 12(7.89%) other 8(5.26%) Prefer not to say 9(5.92%)	Straight 51(73.91%) gay/lesbian 5(7.25%) bisexual 7(10.14%) other 3(4.35%) Prefer not to say 3(4.35%)	Straight 39(73.58%) gay/lesbian 4(7.55%) bisexual 7(13.21%) other 1(1.89%) Prefer not to say 2(3.77%)

* This table shows that the sample, participants who experienced victimisation, and participants with disabilities and experienced victimisation all have minimal demographic differences.

To identify any differences between participants with disabilities who were victimised from other participants with disabilities, the characteristics of these two subgroups were cross-tabulated and summarised in Table 23. Due to its relationship to other findings, further discussion is available in section 5.8.

***Table 23**. Comparison between participants who reported disabilities and the victims among them*

Characteristic	**Participants with self-reported disability (n=102)**	**Victims with disabilities (n=53)**
Demographics		
Gender	Female 79 (77.45%)	Female 43(81.13%)
Ethnic background	White 94(92.16%)	White 48(90.57%)
Age	Range: 18-65 years Mean 36.45(SD= 13.61)	Range: 18-63 years Mean 37.96(SD= 13.10)
Religion	No religion 50(49.02%)	No religion 28(52.83)
Region	England 86(84.31%)	England 44(83.82%)
Employment	24(23.53%)full time employed, 26(25.49%) students 27(26.47%) unemployed, 8(7.84%) part-time 7(6.86%%) self-employed, 10(9.80%) retired	10(18.87%) full time employed, 12(22.64%) students 19(35.85%) unemployed, 3(5.66%) part-time 5(9.43%) self-employed, 4(7.55%) retired
Professions	27(26.47%) professionals 8(7.84%) service/sales 6(5.88%) clerical support 4(3.92%) managers 3(2.94%) technicians/ associate professionals, 1(0.98%) craft/trade 1(0.98%) skilled agricultural or fishery (0.98%) plant/machine operators	12(22.64%) professionals 4(7.55%) service/sales 1(1.89%) clerical support 2(3.77%) managers 1(1.89%) technicians/ associate professionals, 2(1.3%) craft/trade 1(1.89%) skilled agricultural or fishery 1(1.89%) plant/machine operators
Sexual orientation	Straight 72(70.59%) gay/lesbian 8(7.84%)bisexual 10(9.80%) other 6(5.88%) Prefer not to say 6(5.88%)	Straight 39(73.58%) gay/lesbian 4(7.55%) bisexual 7(13.21%) other 1(1.89%) Prefer not to say 2(3.77%)

The cyber-victimisation experience was also compared between all victims and victims with disabilities. These results are shown in Table 24 and discussed in chapter 6. It is of note that the original number of victims (n = 69) and victims with disabilities (n = 53), but the percentages vary in Table 24 due to incomplete responses as explained in section 3.7.

***Table 24**. The characteristics of cyber-victimisation experience among the victims compared to the victims with disabilities*

Characteristics	Victims **not all fields =69	Victims with disabilities n=53
Self-reported victim status	53(76.81%)	37(69.81%)
Fear	Fear/distress 56(81.16%)	Fear/distress 46(86.79%)
Most common mean	Facebook 43(63.24%) *Online health forums 9(13.2%)	Facebook 34(70.83%) *Online health forums 8(16.67%)
Most common duration	More than a year 25(36.76%)	More than a year 18(37.50%)
Most common relation	Stranger 20(29.41%)	16(26.09%)
Relation to condition	Related: 22(41.51%)	18(48.65%)

*This table shows that the experience of cyber-victimisation is comparable between victims with disabilities and the participants who reported victimisation.

The self-management of chronic conditions plan was compared between the whole sample and the victims, the highest frequencies are highlighted in Table 25.

***Table 25**. The self-management plan endorsed by the victims compared to the whole sample*

Victims' self-management	Number of endorsements or entries	% among other endorsements (n=503)	% among victims (n=69)
Lifestyle changes			
Avoiding particular triggers that exacerbate your illness	49	9.74%	71.01%
Healthy eating	39	7.75%	56.52%
Avoiding excessive drinking	37	7.36%	53.62%
Exercise/physical activity	36	6.36%	52.17%
Avoiding smoking	25	4.97%	36.23%
Avoiding particular type of food	4	4.77%	5.80%
Other lifestyle changes	13	2.58%	18.84%
Pharmacological			
Regular medications	51	10.14%	7391%
Medications on need (prescription)	38	7.55%	55.07%
Medications on need (Over The Counter)	11	2.19%	15.94%
Follow up			
Regular follow up with specialist	37	7.36%	53.62%
Regular follow up with GP	39	7.75%	56.52%
Regular follow up with other health care professionals	22	4.37%	31.88%
Physiotherapy	9	1.79%	13.04%
Counselling sessions	17	3.38%	24.64%
Monitoring			
Self-monitoring at home (example: blood sugar)	25	4.97%	36.23%
Regular lab tests	15	2.98%	21.74%
Other			
Alternative/complimentary medicine (such as herbal treatment, aromatherapy, acupuncture)	11	2.19%	15.94%
Other management	9	1.79%	13.04%
Total	503		-

*This table highlights the most common aspects of self-management among the individuals who experienced cyber-victimisation. The highest aspects are highlighted.

To identify the conditions that were more commonly victimised, the conditions were cross-tabulated with cyber-victimisation. Due to the low number, a statistical significance test was not performed. However, the highlighted numbers indicate that 50% or more of the participants with that particular condition were victimised (Table 27). These were mainly asthma, diabetes, depression, COPD, anxiety, MS, ME, fibromyalgia, EDS, and heart disease. Thyroid and IBD were not highlighted because the frequency of victimisation was slightly lower than 50%, but they will be discussed in section 5.7.

***Table 26**. Conditions where more than 50% of the patients were victimised*

Category	**Number of endorsements or entries by all participants**	**Number of endorsements or entries by victims**
Chronic lower respiratory diseases	**53**	
Asthma	45	23
Chronic obstructive pulmonary disease (COPD)	7	5
Lung disease	1	
Endocrine, nutritional and metabolic diseases	**46**	
Diabetes Mellitus	27 *Type I: 17 *Type II: 10	13 *Type I: 7 *Type II: 6
Thyroid disease	18	8
Wilson disease	1	1
Mental and **behavioural** disorders	**46 (13.53%)**	
Generalised anxiety disorder (GAD)	11	6
Obsessive compulsive disorder (OCD)	11	2
Depression	9	9
Unspecified mental health condition	5	3
Autism Spectrum Disorder	4	-
Asperger's Syndrome	3	1
Post-traumatic stress disorder (PTSD)	2	1

Bipolar affective disorder	1	1
Diseases of the skin and subcutaneous tissue	**40**	
Eczema	26	1
Psoriasis	14	5
Diseases of the nervous system	**38 (11.18%)**	
Multiple Sclerosis (MS)	9	4
Myalgic encephalomyelitis (ME)	9	6
Epilepsy	7	4
Cerebral palsy	2	1
Migraine headache	2	2
Cluster headache	1	-
Complex regional pain syndrome	1	-
Balance disorders	1	-
Charcot Marie Tooth	1	1
Dysphasia/Dysphagia	1	-
Essential tremor	1	1
Narcolepsy	1	1
Restless leg syndrome	1	1
Nerve damage	1	1
Diseases of the musculoskeletal system and connective tissue	**36 (10.59%)**	
Rheumatoid arthritis	8	4
Fibromyalgia	6	5
Unspecified arthropathy	6	-
Hypermobility syndrome	4	1
Scoliosis	2	-
Ankle-foot arthrosis	1	-
Gout	1	-
Failed back syndrome	1	1
Soft tissue rheumatism	1	-
Chronic tendinitis	1	1
Spondylitis	1	1
Osteoporosis	1	1
Chronic coccydynia	1	1
Wrist dissociation	1	1
Foot disorder	1	-
Diseases of the digestive system	**24**	
Inflammatory bowel diseases (Crohn's and colitis)	19	8
Irritable bowel syndrome (IBS)	3	3
Intestinal cystitis	1	1

Gallbladder disease	1	1
Diseases of the genitourinary system	**15**	
Chronic renal disease	6	1
Polycystic ovarian syndrome (PCO)	3	-
Urinary incontinence	2	1
Bladder disorders	1	-
Menstrual disorders	1	1
Endometriosis	1	-
Prostatic disorders	1	-
Diseases of the circulatory system	**13**	
Heart disease	6	4
Postural orthostatic tachycardia	3	2
Raynaud's syndrome	2	2
Hypertension	1	-
Vascular disorders	1	-
Congenital malformations, deformations **and** chromosomal abnormalities	**10 (2.94%)**	
Ehlers Danlos Syndrome	8	6
Spina bifida	2	-
Malignant neoplasm	**9**	
Cancer	8	1
Post-chemotherapy complications	1	-
Disorders of the ear and mastoid process	**4**	
Impaired hearing/deafness	3	1
Tinnitus	1	-
Diseases of the eye and adnexa	**3**	
Retinopathy	1	-
Impaired vision	1	-
Corneal diseases	1	-
Injuries and consequences of external causes	**3**	
Spinal injury	2	1
Lower leg amputation	1	1
Total	**340**	

* This table gives a general idea on the conditions that were more commonly victimised. It is not conclusive, but the highlighted conditions require further research.

4.2.6.2 Disability cross-tabulations

Disability status emerged as one of the key findings in scoping cyber-victimisation (section 4.2.1.1). Hence, further interrogation of data was made solely on victims with disabilities.

Of those who self-reported living with a disability, 79 (77.45%) were females, 21 (20.59%) were males and 2 (1.96%) did not specify gender. Upon diagnosis, 90 (88.24%) experienced fear. Of the participants with disabilities, 53 (51.96%) were cyber-victimised, and 40 (39.21%) self-reported victim status. This indicates that almost one in every two people with disabilities was victimised, equating to 76.81% of the 69 victims in this study. Among 51 victims, 96.08% experienced fear, reflecting disruption and could be linked to themes 4 and 6. The diversity elements of participants with disabilities and those who were victimised were summarised in Table 24; this included age, gender, and ethnicity. The findings are further discussed in chapter 6. The harassers, in this case, were also strangers and was mostly on Facebook, with a long duration as reported in Table 24 and discussed in section 5.5.

In terms of the impact of cyber-victimisation, 26 of 39 (66.67%) disabled victims thought it affected their health, with 19 of 38 (50%) disabled victims considering that they were a target due to their health condition. Of those, ten (26.32%) have spoken to their GPs about this impact, with two rating the support very good, one rated it good, four fair, and three rated it poor.

4.2.6.3 Statistical significance tests

The first independent variable used was gender, as there is controversy in the literature regarding this variable (section 2.4). Among those who perceived that the targeting was related to their conditions, 17 (77.27%) were females. According to the chi-square test, as shown in Table

27, the p-value is .607946, hence, the relationship between gender and being cyber-victimised was not statistically significant.

Table 27*. The relationship between gender and cyber-victimisation is not statistically significant*

Category	Cyber-victimisation	No cyber-victimisation	Total
Male	12 (13.23) [0.12]	17 (15.77) [0.1]	29
Female	56 (54.77) [0.03]	64 (65.23) [0.02]	120
Total	68	81	149

The chi-square statistic is 0.2632, the p-value is 0.607946, so this result is not significant at $p < 0.05$.

To test for the relationship between gender and the perceived impact on the self-management of the chronic conditions, the Fischer exact test was used as explained in section 3.3.5. However, the result was 1.0 which was not statistically significant as shown in Table 28. Thus, no significant relationship was found between the gender and reported impact.

Table 28. *The relationship between gender and cyber-victimisation impact is not statistically significant*

Category	Cyber-victimisation	No cyber-victimisation	Total
Male	5	3	8
Female	28	15	43
Total	33	18	51

The Fisher exact test statistic value is 1. The result is not significant at $p < .05$.

Disability status was used as an independent variable to check for the relationship with cyber-victimisation experience. The result of the chi-square test was 5.0227, the p-value was

0.025018, which was significant at $p < 0.05$. Hence, there was a statistically significant relationship between self-reported disability and cyber-victimisation.

Table 29 *The relationship between disability and cyber-victimisation is statistically significant*

Category	Cyber-victimisation	No cyber-victimisation	Total
Disability	53 (46.81) [0.82]	49 (55.19) [0.69]	102
No disability	14 (20.19) [1.9]	30 (23.81) [1.61]	44
Total	67	79	146

The chi-square statistic is 5.0227. The p-value is .025018. This result is significant at $p < .05$.

However, despite the statistical significance, the impact of cyber-victimisation on perceived changed to the individual self-management of the impairment was not statistically significant when victims with disabilities were compared to victims without disabilities. The p-value using the chi square test was 0.187986, which was not significant at $p < .05$. Thus, the impact of cyber-victimisation was irrespective of disability status as shown in Table 30.

Table 30. *The relationship between disability and cyber-victimisation impact is not statistically significant*

Category	Impact	No impact	Total
Disability	26 (24) [0.17]	13 (15) [0.27]	39
No disability	6 (8) [0.5]	7 (5) [0.8]	13
Total	32	20	52

The chi-square statistic is 1.7333. The p-value is .187986. This result is not significant at $p < .05$.

The sexual orientation diversity was also examined as a potential factor but not statically significant as illustrated in Table 31.

Table 31. *The relationship between sexual orientation and cyber-victimisation is not statistically significant*

Category	Cyber- victimisation	No cyber-victimisation	Total
LGBT	10 (11.73) [0.26]	12 (10.27) [0.29]	22
Heterosexual	62 (60.27) [0.05]	51 (52.73) [0.06]	113
Total	72	63	135

The chi-square statistic is 0.6555. The p-value is .418143. This result is not significant at $p < .05$.

The relationship between fear and self-reported victim status was statically significant, as illustrated in Table 32. Of the eight participants who did not experience fear, five considered themselves as 'victims' and two were not sure about their victim status.

Table 32*. The relationship between fear and self-reported victim status is statistically significant*

Fear	Self-reported victim status	No self-reported victim status	I don't know	Total
Extreme fear	21	1	0	22
Moderate fear	18	5	1	24
Slight fear	6	7	1	14
No fear	5	2	1	8
Total	50	15	3	68

The chi-square statistic is 13.8274. The p-value is 0.032. This result is significant at $p < .05$.

Note that six out of the ten participants who did not know whether they were victims, answered yes to the cyber-victimisation criteria. Fear was also statistically significant in relation to the impact of cyber-victimisation as shown in Table 33.

Table 33 *The relationship between fear and perceived cyber-victimisation impact on self-management is statistically significant*

Fear	Cyber-victimisation impact	No cyber-victimisation impact	Total
Extreme fear	16	1	17
Moderate fear	12	6	18
Slight fear	4	7	11
No fear	1	7	8
Total	67	21	54

The chi-square statistic is 18.8160. The p-value is 0.000. This result is significant at $p < .05$.

The age range of victims was 18-63 years, with an average of 36.87 years (SD =12.56). When cross-tabulated, 56 (81.16%) of cyber-victims were females and 53 (76.81%) of the victims were disabled. In terms of sexual orientation, 12 (17.39%) of victims were gay, lesbians or bisexual. When cross-tabulated with gender, 9 participants out of the 13 who told their GPs were females.

The relationship between employment and cyber-victimisation was examined using the chi-square test, the p-value was 0.217, so was not statically significant, as shown in Table 34.

Table 34 *The relationship between employment and perceived cyber-victimisation impact on self-management is not statistically significant*

Employment	Cyber-victimisation impact	No cyber-victimisation impact	Total
Full time	4	9	13
Part time	3	1	4
Retired	2	2	4
Self-employed	4	3	7
Student	6	7	13
Unemployed	2	11	13
Total	21	33	54

The chi-square statistic is 7.0554. The p-value is 0.217. This result is not significant at $p < .05$.

With regards to the duration of cyber-victimisation, it was examined in relation to cyber-victimisation impact. The chi square test was not statistically significant, with a p-value of 0.203.

Table 35. *The relationship between duration and perceived cyber-victimisation impact on self-management is not statistically significant*

Employment	Cyber-victimisation impact	No cyber-victimisation impact	Total
From 2 weeks to 4 weeks	3	5	8
From 3 months to one year	7	5	12
From 5 weeks to 2 months	4	3	7
Less than 2 weeks	3	4	7
More than a year	16	4	20
Total	33	21	54

The chi-square statistic is 5.9460 . The p-value is 0.203. This result is not significant at $p < .05$.

However, the duration was revisited after theme 1 on the biomedical events emerged in section 4.3, and highlighted the late realisation of the impact on health. When the categories were narrowed to a year or less compared to more than a year, there was a significant relationship with the impact. Duration was also significant with self-reported victim status as shown in Table 36.

Table 36*. The relationship between duration and perceived cyber-victimisation impact is statistically significant when the duration of cyber-victimisation was categorised into less/more than a year*

Category	Cyber-victimisation impact	No cyber-victimisation impact	Total
One year or less	17 (20.78) [0.69]	17 (13.22) [1.08]	34
More than a year	16 (12.22) [1.17]	4 (7.78) [1.83]	20
Total	33	21	54

The chi-square statistic is 4.7688. The p-value is .028979. This result is significant at $p < .05$.

Accordingly, the participants who experienced cyber-victimisation considered themselves "victims" when the duration was longer. This relationship between the duration and self-reported victim status was statistically significant as reported in Table 37.

Table 37. *The relationship between duration and perceived cyber-victimisation status is statistically significant*

Duration	Self-reported victim status	No self-reported victim status	Total
From 2 weeks to 4 weeks	7	4	11
From 3 months to one year	11	1	12
From 5 weeks to 2 months	3	5	8
Less than 2 weeks	7	2	9
More than a year	22	3	25
Total	50	15	65

The chi-square statistic is 11.2993 . The p-value is 0.023. This result is significant at $p < .05$.

4.3 Qualitative results

A total of thirteen in-depth interviews were conducted with victims of cyber-victimisation who were living with long-term conditions or disabilities. Table 38 summarises the code used for each interviewee and the main points about their experiences. From these interviews, six themes emerged. The qualitative data collected in the first phase was thematically analysed and cross-checked with the themes from the interviews. The themes below describe the patterns in the data and the commonality across the datasets. Quotations from phase one are coded with the letter A, and those from the second phase are coded with the letter B.

Table 38. *The characteristics of the interviewee in phase two. The table provides the main demographic information, the conditions the interviewee had and a summary of the cyber-victimisation experience.*

Interviewee	Age	Gender	Ethnicity	Conditions	Cyber-victimisation experience
B1	27	Female	White	Diabetes type I	Cyberstalking by ex-partner
B2	45	Female	White	Asthma, COPD, eczema, IBS	Cyberstalking by a stranger
B3	36	Female (gay)	White	Congenital bone disease, asthma, eczema, gynaecological problems, sinus problems, anxiety, migraine headache.	Multiple incidents of cyber-harassment/disability hate
B4	60	Female	White	ME/Fibromyalgia, spinal injury	Cyberstalking in an online support group, cyber-harassment in an online support group
B5	29	Female	Latino	Epilepsy, depression, (and PTSD)	Cyberstalking by a work colleague
B6	52	Female	White	Adrenal fatigue, hypothyroidism (and PTSD)	Cyberstalking by ex-husband
B7	56	Female	White	Depression, essential tremor, restless leg syndrome, diabetes II	Cyberstalking/cyber-harassment by someone who had affair with the husband.
B8	59	Female (Gay)	White	Angina (rare form), mini-strokes, asthma, COPD, thyroid disease, urinary incontinence, gastric condition, unilateral blindness	Multiple occasions, hate-related, most recent is an online support group/disability campaign.
B9	40	Female	White	Thyroid disease, depression,	Multiple-harassment by family.

				anxiety, CSF, osteoarthritis, IBD	
B10	34	Female	White	Eczema, mental health	Cyberstalking by ex-partner.
B11	51	Female	White	Asthma, bipolar disorder	Cyberstalking by a man who got involved with.
B12	48	Male	African	Depression	Cyberstalking following an incident at work.
B13	53	Female	White British Anglo-Indian	Psoriasis and psoriatic arthritis	Cyberbullying by the work manager

**The codes B1 to B13 were given to the participants to ensure anonymity.*

Theme 1: Biomedical Events

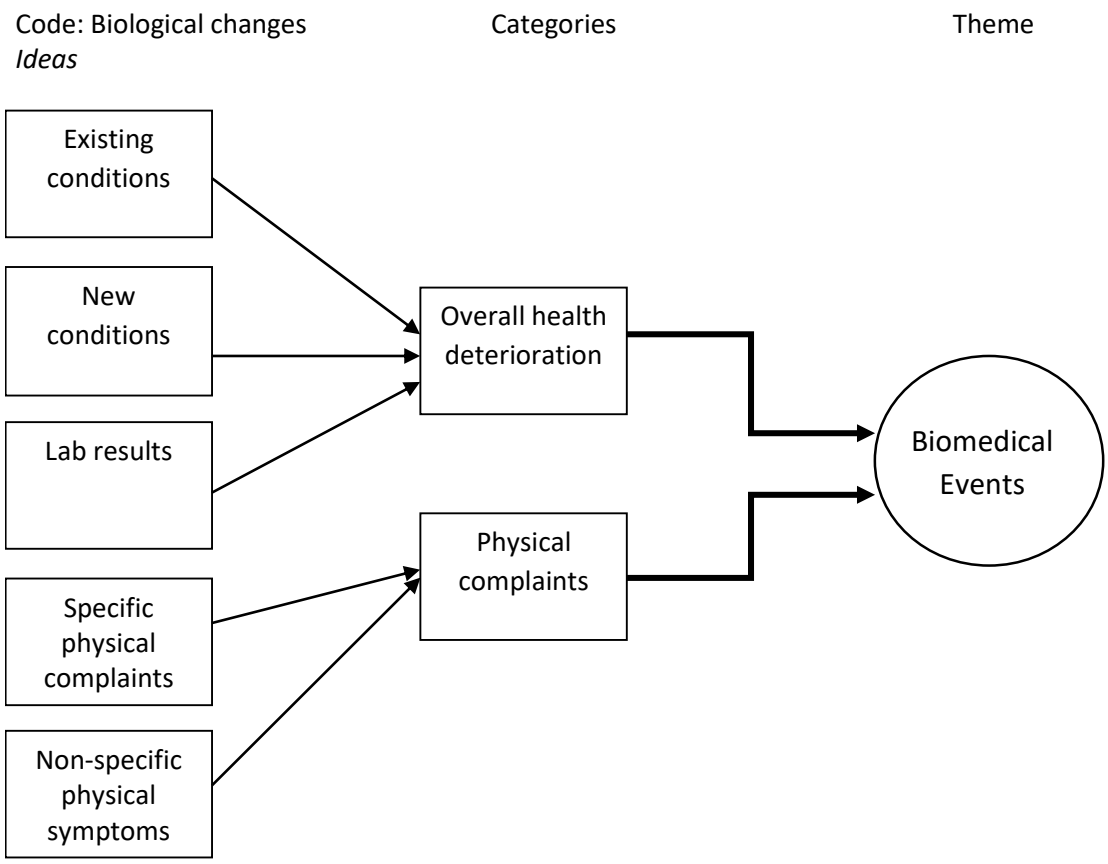

Figure 14. The development of theme 1

This theme is centred on the physical health consequences experienced by the participants following cyber-victimisation. Most of the participants attributed these events to the victimisation itself. However, the acknowledgment of the physical impact often happened at a later stage, after a relatively long duration of cyber-victimisation campaigns. The participants eventually realised its effects on their physical wellbeing, which was one of the factors that encouraged them to participate in this study. Hence, most participants were concerned about their chronic conditions, but they mostly shared these issues in brief recurrent sentences compared to other themes.

> ‘I cannot officially report it and until last few days didn't realise how badly it affects my health’ Participant A43

> ‘I felt betrayed embarrassed stupid and desperate because I responded to those texts and emails at all times of night and day and let them take over my life at the expense of family friends and my own well being.’ Participant B13

Biomedical events took several forms, the most common category was the ***overall health deterioration.*** Most victims perceived poor prognosis in their long-term conditions and described their physical health in general as worse, terrible or going downhill. In this aspect, the impact of this experience was perceived in relation to the existing health condition, developing new conditions and changes in lab results.

The participants were living with chronic health conditions when they first experienced cyber-victimisation. Accordingly, they described variable health complications that corresponded to their specific health conditions. Diabetes mellitus was present over all the categories in this theme, and the participants experienced an exacerbation of diabetes symptoms during and following cyber-victimisation. The impact was not specific to diabetes, it was also associated with other physiological systems. Patients with respiratory diseases, such as asthma and COPD, reported an increase in their recurrent infections and rib cage problems, while participants with neurological conditions experienced changes in their symptoms, such memory issues and visual disturbances. In this category, patients with epilepsy shared a change in the frequency or the type of seizures compared to their conditions before cyber-victimisation.

> ‘I don't have the full blown ones often, what I have because of my visual cortex effect. I see flashing dots all the time. That's the type of seizures I have but sometimes very stressful situations can trigger the full-blown seizures and I've had those in July 2015. I had nearly thirty seizures in one week, I was sent to hospital and that was stress related so at the moment of stalking and everything I have to really be careful of this stress and that's how it goes to full blown seizures.’ Participant B5

Patients with thyroid conditions frequently stated that the seriousness of the condition had changed from mild/moderate to severe. In the cases where patients had musculoskeletal conditions, most of them experienced musculoskeletal upset, for example, participants coping with ME. Patients with fibromyalgia also reported a higher level of chronic pain.

> 'Chronic pain of fibromyalgia and arthritis also got worse due to bullying and stalking' Participant B9

Other concerns categorised under the overall deterioration of health were the development of new physical health conditions on top of the existing ones by some participants. They were mostly diagnosed with primary headaches, such as migraine. As most participants had multiple co-morbidities, they perceived that they developed some of these chronic conditions concurrently with the cyber-victimisation experience. This experience-blaming approach was common in cases of type 2 diabetes. However, this was also reported by one participant living with osteoarthritis, he blamed the cyber-victimisation experience and its long duration for the development of this painful condition.

> 'Was an extremely stressful time and symptoms of diabetes began at that time. Discrimination has made me very ill.' Participant A227

> 'I was doing ok with my health until the stalking started. After 2 yrs I was diagnosed with PTSD for which I received no treatment. The stalking was so terrifying that I developed rheumatoid arthritis after about 6yrs of it. Ditto, no treatment.' A72

Some participants demonstrated changes in their overall health condition through the deterioration of their follow up and lab results; this was common in patients with diabetes and thyroid disease.

The second category in the biomedical events was reporting ***physical health complaints.*** These symptoms could be divided into non-specific and specific health complaints. Non-specific

health complaints in this theme refer to a group of subjective physical symptoms that are variable and not consistent with the diagnosed disease prognosis. Most participants described experiencing some or all of these symptoms, such as palpitations, excessive exhaustion, loss of consciousness, appetite and weight changes, or vomiting. Specific health complaints refer to the symptoms relevant to the diagnosed health conditions. These groups of participants described more specific symptoms related to the worsening of their conditions, such as patients with irritable bowel disease and epilepsy.

> 'It was quite difficult actually, it was very difficult, it increased my stress levels, which obviously also doesn't go along with angina but I realised that it has had affected my health' Participant B8

> My health suffered hugely. I was prescribed anti-depressants, but they gave me horrible nightmares on top of the ones I was already having. My weight began to increase alarmingly, despite not eating much. Lack of sleep and constant hypervigilance made me exhausted. I started getting pains in my joints and large muscles – this was my hypothyroidism and adrenal fatigue returning. I began to suffer debilitating migraines and was taking maximum doses of Sumatriptan to manage these mercifully, this medication was effective. My stalker knew full well that he would make my hypothyroid condition worse (…) he did the same to a previous partner when she had breast cancer. I consider his actions attempted murder. I am still trying to recover my physical (thyroid and adrenal) and mental (PTSD) health.' Participant B6

In a negative instance, one participant with a congenital bone disease did not perceive a link between physical health and being cyber-victimised. The participant thought that cyber-victimisation could have an indirect impact on health through stress, but it will not cause her bones to break.

> 'it's not like someone bullying me it makes my bones break more easily, it doesn't work like that, but yeh it made my anxiety disorder much worse because I was in actual danger if they found my address' Participant B3

Other victims were aware of the impact of stress on their chronic condition, particularly those with heart diseases and IBS. The perception that these physical complaints were secondary to their level of stress will be further discussed in theme 2.

Theme 2: Impact on Mental Health

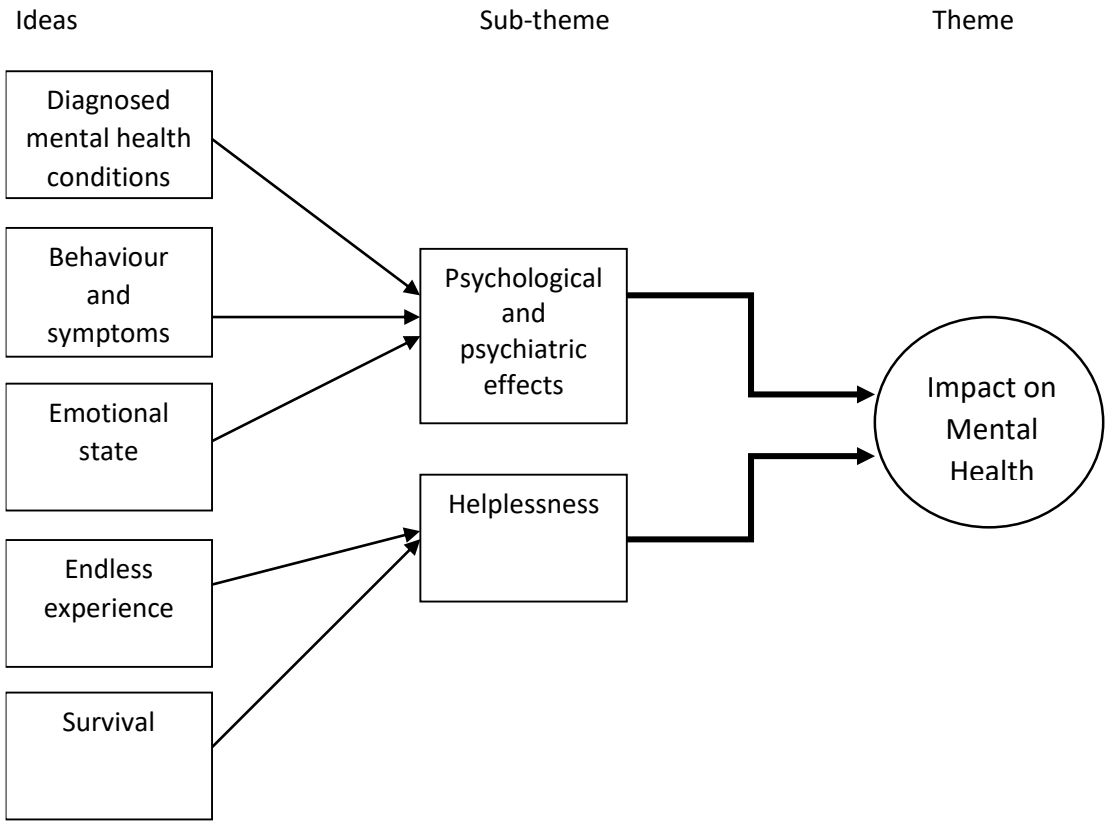

Figure 15. *The development of theme 2*

The central concept of this theme is the severe psychological and mental health impact imposed by cyber-victimisation on the victims. All participants shared their experiences in this regard. The responses were across the two sets of data, and ranged from repeating words to detailed descriptions, crying and sharing suicidal thoughts or attempts. In this theme, two subthemes were identified: psychological and psychiatric effects, and helplessness.

In the **psychological and psychiatric effects** subtheme, the impact was observed in most participants through the sharing of a range of emotions, compulsions and stress-related behaviours, as well as developing mental health conditions. Most participants were diagnosed

with a mental health condition by healthcare professionals secondary to cyber-victimisation. The most common conditions were PTSD, depression and anxiety. A participant with bipolar disorder stated that:

> 'Due to all the abuse and various other stressors, I had a psychotic breakdown in 2009. It was only then I sought treatment and was diagnosed. …… I believe I'm permanently psychologically damaged' Participant B11

Some participants were already living with anxiety or depression prior to being victimised. In these cases, the victims experienced deterioration of these conditions after their experience. Some of them developed new mental health conditions too, for example, developing PTSD on top of depression.

> 'I was diagnosed with anxiety and depression, this increased my daily medication and led to mobility problems I had not experienced before' Participant A230

> 'I just had uh (..) the emergency response team and a mental health team had to come in on two occasions to save me at home and then they put me on tranquilizers and put more antidepressants so. And that was for about two weeks, they were coming everyday for like two weeks until I was more stable again. That's happened twice I've had a mental collapse' Participant B7

> 'My depression has made my illness worse, and police have done nothing to stop it even with a restraining order, I often get discriminated against online facebook etc. for not working and made fun of but they caused it to get this bad , I live with that every day ... it made me ill and more ill' Participant A158

The emotional state of most participants was disturbed. The victims stated explicitly and repeatedly experiencing high levels of stress due to cyber-victimisation. This was shared through a range of feelings such as being worried, frustrated, stressed, scared, terrified, on the edge,

dread, upset, or distressed. Some victims felt angry and hurt, while some other participants said they felt 'vulnerable'.

> 'when one of these people contact me and it's like you know to tell me you've got a message, the feeling of dread every time that happens, you know, it's it's extra stress, extra worry, I I have nightmares about it, I, I thinks it's really badly affects me stress wise.' Participant B2

Consequently, the participants experienced stress symptoms and the behaviour of victims was subsequently influenced. The symptoms included a racing heart beat, insomnia, hyper vigilance, and rumination. Receiving the harassing messages was described to be very stressful, this was mostly accompanied by obsessions and compulsions to check. Some participants had the urge to check their emails or phones, and in this case, some of them were frequently checking the harassing messages, and others attempted to ignore them, however, both approaches caused more distress. Other participants described their status as being tearful, jumpy, obsessive or paranoid, while others thought that the idea of seeing their harassers as an intense situation that could drive them mad.

> 'The stress experienced exacerbates the ME symptoms and depression. My anxiety levels are a lot higher which affects my sleep patterns and appetite. Exhaustion and pain is extreme.' Participant A232

> 'I had mental health problems prior to being stalked but the stalking that has taken all forms has been happening since I was 25 and it is still happening today and my patience is wearing thin. I am constantly crying.' Participant B10

Some participants shared thoughts of self-harm, which involved suicidal ideation and/or attempts secondary to being cyber-victimised. This was observed in the cases of cyberstalking or multiple incidents of cyber-harassment.

> ‘I had a massive trigger – shaking, anxiety, panic attacks, vomiting. I instantly became hyper-vigilant, leading to paranoia, insomnia and obsessive behaviour, laying 'traps' to see if anyone had been into my room etc. I was constantly frightened. I became very withdrawn, depressed and on 2 occasions felt suicidal, needing attendance at A&E and Crisis Team.’ Participant B6

The ***helplessness*** subtheme emerged from the point where the victims felt cornered and their subsequent reactions. Most participants were overwhelmed by the experience of cyber-victimisation and were struggling to deal with it. The victims perceived cyber-victimisation as an endless experience that would never go away, they ran out of options, and that their harassers were everywhere. The reactions to this point were different, most participants thought there was nothing that could be done to help them, which in some cases lead to suicidal thoughts. When asked about the impact of cyber-victimisation, one participant stated:

> ‘Chronic ptsd and feelings that this will never end’ Participant A176

> ‘Mentally I became very vulnerable and unstable. I felt he was watching me everywhere I went. I became jumpy, bad-tempered and isolated. I felt that if I spoke to anyone, it would get back to him. I spent a lot of time trying to anticipate and second-guess what he would do next. This made me physically and mentally ill.’ Participant B6

> ‘it's like you've got your hands tight you can't fight back, there is nothing I can do at all. There is nothing I can do (crying) and she can do all this and. And there is no coming back’ Participant B7

However, a group of participants perceived helplessness as a survival issue, in which either the harasser or the victim can stay, or the harasser is intentionally intimidating the victim to commit suicide. Alternatively, in order to survive, some participants acknowledged their need to stand up for themselves and found their own ways to fight back. The approaches adopted by the victims were the social model of disability, as starting campaigns for disability rights or against the police, or approaching human rights organisations to support their individual cases.

> ‘it's because I think it's disgusting. You know it's not acceptable. We're told it's our right. So I spoke to this human rights […] and they got a template for sexual harassment and I told (my employer) look it's my rights as a woman as a human being. This is a human right issue now,

> because, you know, my life is in danger and I want to make a formal complaint against this person. So I was really unwell, you know, because of my epilepsy, you know, I know the stress' Participant B5

> 'I subscribed to the social model of disability um that's the sociological concepts that ummm you are a smart person working in research, but yah, I mean, I have no issues with my rubbish bones from a personal perspective but you know I live everyday with the society-created problems, because we live in a world that hates disabled people' Participant B3

However, in spite of adopting the social model of disability by most victims, one victim shared on behalf of ME patients that they are fighting the psychosocial approach in categorising ME, and they preferred the medical categorisation that ensures treating it as a neurological disorder and reduces labelling by the society.

> 'Another unusual aspect of ME is that we are fighting a battle against the psychosocial model that has been foisted on us. Although ME is classified by World Health Organisation as a neurological condition, in UK it is treated as psychological, so we are always fighting the misinformation, medical mistreatment and belittling of our condition' Participant B4

Theme 3: Multifaceted Disruption

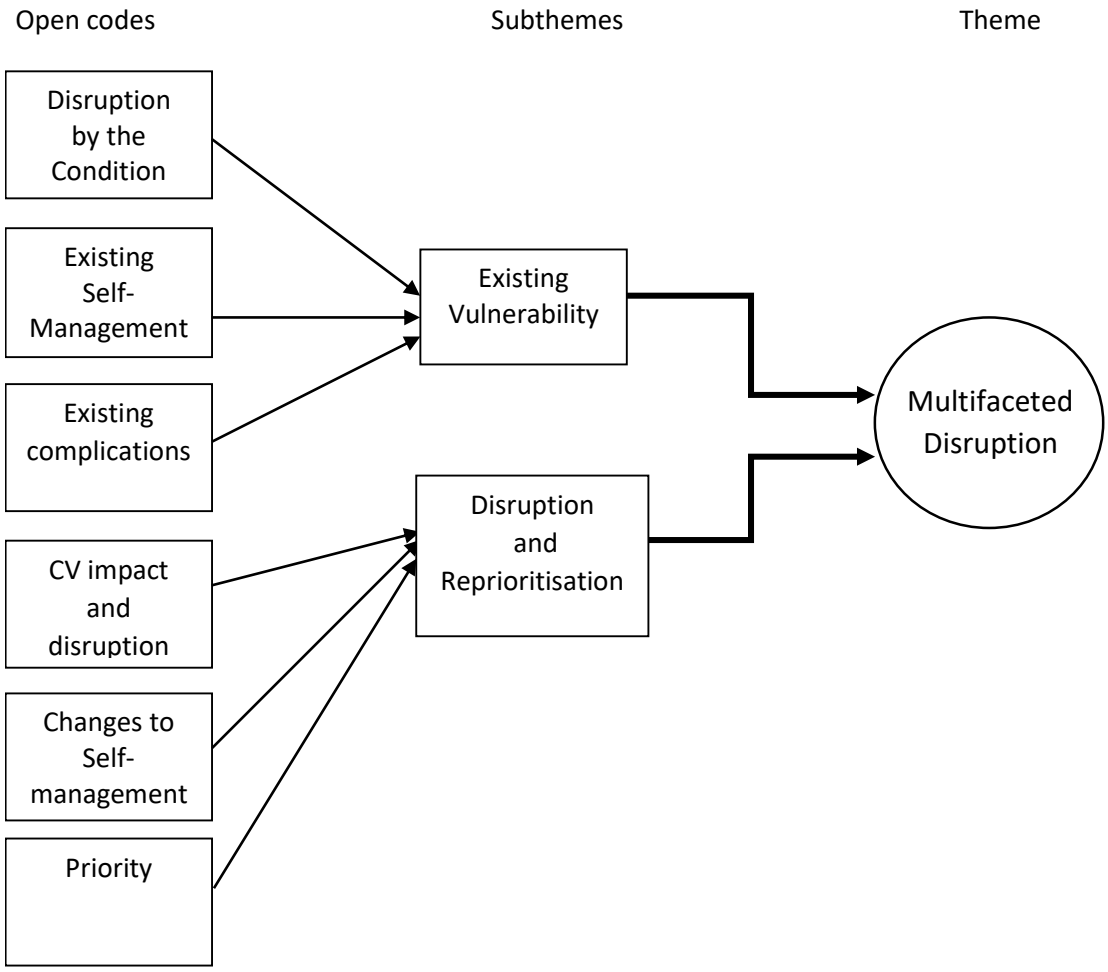

Figure 16*. The development of theme 3*

The central concept in this theme is the impact of cyber-victimisation on the chronic condition management plan. The impact was found to be multi-level involving several aspects. All participants shared perceived changes to their management plans, some of which were also influenced by existing circumstances. In most cases, there were pre-existing disruptive influencers on the self-management, which were further disrupted by the cyber-victimisation experience. The levels affected were related to the diagnosis of the condition itself, coping and

management, and how these were affected by the experience directly or indirectly. Two subthemes were identified under this theme: existing vulnerability, and disruption and reprioritisation.

The ***existing vulnerability*** subtheme is focused on participants' descriptions of the disruption they had to deal with when the chronic condition was diagnosed. It also reflects their continuous effort to accept the diagnosis, manage complications, and cope with them daily. The disruption by the condition emerged from participants' reaction to their diagnoses. Different responses were shared depending on the nature of the condition, circumstances surrounding the diagnosis and the age of participants. Some of them were shocked, surprised or disappointed,

> 'My emotional response to most of these illnesses / conditions is very similar to the Kübler-Ross model of grief; indeed, I am grieving for the person I was, for the person I still should be. It has taken a few years to get to some sort of acceptance, yet even now I do have problems accepting that I will never get better, only ever worse. Sometimes I cry with frustration' Participant B4

Others were relieved by the diagnosis, due to going through numerous processes and misdiagnoses or because it formally gave a name to their conditions. Hence, as they perceived, they will not be labelled as lazy or fat anymore.

> 'When I finally got my hypothyroidism diagnosis I felt quite relieved. I knew there was something wrong but had been repeatedly labelled by mainstream medicine as 'fat and lazy', despite spending my youth and 20s being sporting and active. So the diagnosis felt like a victory […] The PTSD diagnosis was no surprise, given the trauma I'd been through. Again, it was a relief to 'put a label on it' and realise that it is normal in the circumstances' Participant B6

Participants who developed their conditions at a very young age could not imagine living without impairments or ill health. However, the impact and struggle to cope was shared by both those who were diagnosed at older and younger ages.

> ‘I have no idea about living without a bone disease because I had it my whole life and asking me about that is like asking a disabled person about being non-disabled’ Participant B3

> ‘Especially when you're a teenager and then you're playing with your friends and all of a sudden you know you don't have any memory or anything, and you know when you have a seizure when you're like a teenager or an adult it does have an impact on your life’ Participant B5

Another form of disruption by the condition that followed the diagnosis was the prognosis and complications. Even in cases where the condition was bio-medically controlled, the patients experienced effects on their lives. This had a physical aspect due to restricting physical movement in some conditions and difficulty to perform some activities. Other facets included changes in memory or social lives. Some participants were dealing with existing complications such as hospitalisation, the progression of diabetic retinopathy, or loss of energy.

> ‘I try to manage it most of the time but you can’t manage it, that’s the problem, you can’t manage it. I get attacks all the day’ Participant B8

With the disruption by the condition and existing complication, the self-management of the condition was already not stable in most participants. The reactions to the existing self-management plan ranged from accepting the condition and living with it, to the denial of having a chronic condition and facing challenges in coping. In the case of challenges in coping, some participants hated the impairment, experiencing multi-level impact from childhood to adulthood. Some were embarrassed and did not want to talk about the condition, expressed being ashamed of managing it or chose to deal with it privately. Others had to create new lives online through incorporating the illness into their online identities to cope. Others used online services, such as online shopping, to overcome

physical obstacles. Some participants chose to have a predominately online life because people online would not be aware of their health problem.

> ‘People with a chronic illness are, quite literally, sitting targets. We depend on the internet for socialising, and for support groups. If someone takes advantage of someone else on there, it takes away the element of trust and support, so increases the loneliness and isolation of those already suffering.’ Participant A05

> ‘I don’t get out much my entire life is online so I’m even more isolated than I was before’ Participant B3

However, being entirely online brought risks too. One participant mentioned the vulnerability online. When asked about vulnerability from this participant’s perception, she explained some social life difficulties in addition to the disabling condition she had.

> ‘Disagreed with him he then targeted the most vulnerable admin of the group and we had to put in a police compliant.’ Participant B8

This theme showed the existing circumstances around having a chronic condition and being targeted. However, the participants had different understandings of vulnerability, as will be covered in theme 6.

The ***disruption and reprioritisation*** subtheme represents the point where cyber-victimisation was introduced as a disruptive event in addition to the previous disturbing subtheme. It reflects the participants’ accounts on the impact of cyber-victimisation on their self-management plan directly or indirectly.

The victims shared an overall change to their health management, this was a multi-level change that included parts or all of the management plan, and varied among participants. Some of them described undesirable adjustments that caused a transition from controlled to an

uncontrolled chronic condition. Others shared expressions such as the difficulty to cope anymore, struggle to recover physically and mentally. The stated changes to managing the health condition included non-planned lifestyle modifications such as dietary changes or physical inactivity that contradicts health needs. The changes also included taking more medications, such as pain killers or antidepressants, which triggered side effects including nightmares or exacerbating epileptic attacks.

> ‘I couldn't manage I gave up trying and it got worse After I gave up and took too many pain killers and didn't have a plan for about eighteen months’ Participant B13

The follow up of participants was also affected, less interaction with healthcare practitioners or lab testing was shared by some patients. However, some victims had more encounters with healthcare professionals, especially psychotherapists.

> ‘So I think because my mental health went down, my physical health went down, I didn’t go out, stayed in, dont do any exercise, so I think it’s all snowballed .. So yeah it's affected It's (..) Because I'm not sleeping in my sleep is eratic, so my eating patterns is erratic’ Participant B7

Another prominent finding in this theme is a reprioritisation process. In this process, health and self-management went back in the victim’s priority list, while the cyber-victimisation became their primary focus. Most participants started to forget to care for self, skip meals, ignored blood tests or acknowledged general non-adherence or indifference about managing their chronic condition. Other participants started avoiding being outside for exercise due to the impact of cyber-victimisation.

> ‘When it’s happening, when I’m receiving these things and when I’m stressed about it my diabetes become, goes back to my mind, like it’s not a priority so I won’t think about blood testing or I might not feel hungry, so when I have a meal I don’t do a blood test so the impact of stress on it makes me sort of forget to do that sort of side things.’ Participant B1

However, in one response, the forgetfulness was as a result of biological changes due to having epileptic seizures.

The disruption caused by cyber-victimisation also included other indirect dimensions, such as work, many participants ended up unemployed due to the impact it had on them. One participant was denied promotion because the harassment was at the workplace, and the harasser was a superior who used her disability as an excuse, hence she had to rely on support for some time. The second dimension was related to victim's living conditions, some of them were too afraid to leave home, others moved, with some ending up homeless and one participant had to leave the country. Due to these consequences on work and home circumstances, some participants shared explicitly that cyber-victimisation had ruined their lives.

> 'found work outside the UK but the mobbing continued and I had to return to the UK when my contract in Singapore finished and I couldn't find another. On my return I entered repetitive depressive cycles due to this unemployment.' Participant B12

Another dimension was the impact on communication. Most participants had to change their emails, phones or close accounts such as social media accounts or Skype. This imposed enormous impact on some participants who relied on these methods to communicate with their family and friends.

> 'I've locked down everything but because I'm an online person, I work online, I do marketing, so I can't, and I don't really want to lock myself away, I haven't done anything (trembling/crying).' Participant B7

> 'I had to close my Skype account. I had to delete it because every day he sends me messages with different fake profiles on Skype and I use Skype to speak to my family in Brazil. So for me to close my Skype account was a big big thing' Participant B5

Theme 4: The impact of complexity

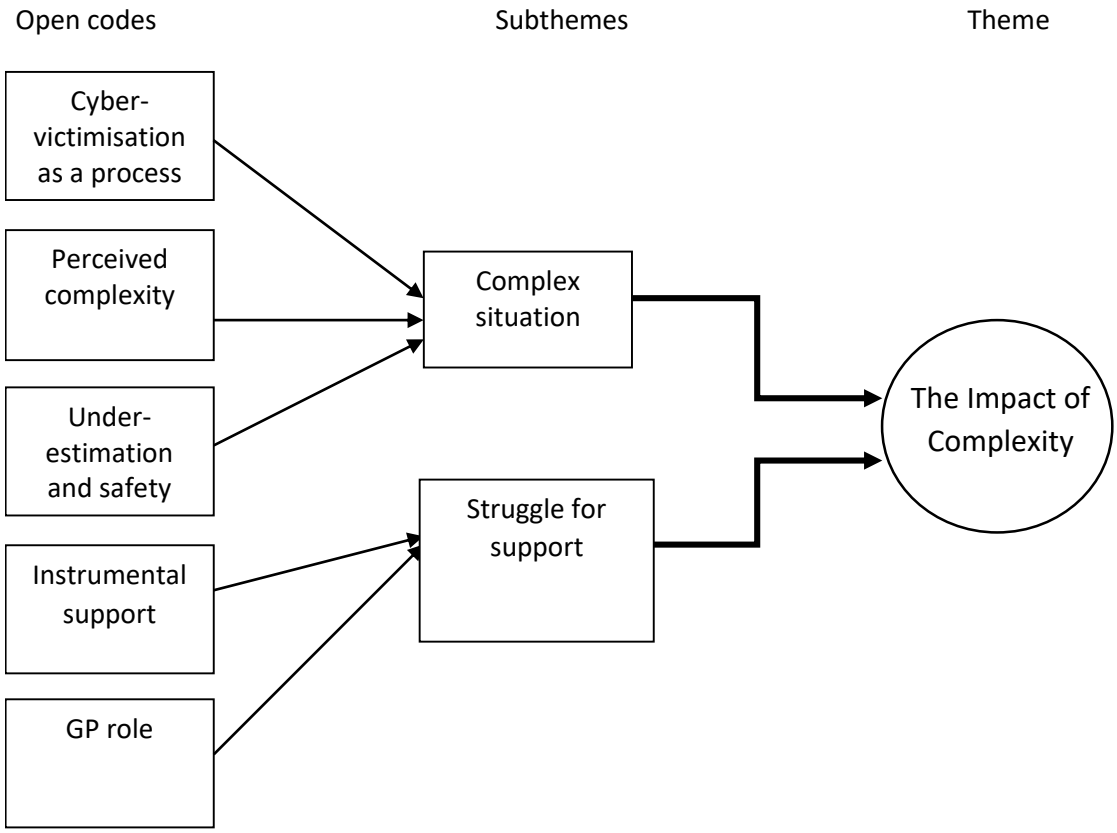

Figure 17. *The development of theme 4*

The main idea in this theme is the perceived complexity of the individual cyber-victimisation cases and victims' attempts to get support. The theme reflects the indirect impact of cyber-victimisation experience on self-management; by precipitating mental health impact (as covered in theme 2), or influencing follow up (as covered in theme 3). Two subthemes emerged: complex situation and struggle for support.

The ***complex situation*** subtheme explores the cyber-victimisation process as described by victims coping with long-term conditions. It also covers the details influencing the uniqueness of each case, as well as safety concerns.

The process of cyber-victimisation was described using using different phrases by victims, but they shared similarities in patterns. The details of each case included: describing the whole experience, harasser's portrayal, motives, attitude, method of contact and the distressing content. Most victims could not explain the experiences they went through, they labelled it as an ongoing cycle, with on and off patterns. Furthermore, they referred to their harassers as abnormal, crazy or with mental health issues. The harasser's attitude was also volatile, ranging between the expressions of love to hate. Some harassers threatened to kill themselves, while others threatened to hurt the victims or encouraged the victims to harm themselves. Accordingly, the perceived motivation ranged from getting a reaction from the victims, wanting a relationship, to intimidation, hate and mass harassment.

> 'She'd like told me about online, you should try hard next time, when I tried to kill myself. Try hard next time (cry).she's like, I don't know why she's like that, it's just horrible.' Participant B7

> 'Whilst I was struggling to survive on very low income, in inadequate housing and with an increasingly complex mental state. I felt abandoned to my fate, and that my stalker was going to achieve his aim – for me to kill myself.' Participant B6

In some cases, the harassers blamed the victims or went through circles of abuse followed by apology. The content of the messages or calls included insults, threats, sexual references or far photographs. Consequently, the pattern of contact, content and perceived motivations left the victims in a state of anticipation and facilitated stress-induced impact.

> 'It is still ongoing, it's nearly a year now umm it's very very stressful, it's non stop sexual references you know accusing me stuff making it all being my fault you know that I'm supposed to be in love with this guy (..) I have never met him I don't know him" Participant' B2

The perceived complexity emerged from participants' accounts, when they felt their situations were different from others due to the specifics of each case. Hence, despite being different, the victims shared the thought that their cases were unique. One aspect was related to work and organisational reputation, such as working in sensitive organisations with political involvement. or when the harasser were co-workers in well-known organisations . Some participants worked in administration in online support groups, hence, when they faced harassment there responsible for challenging the harasser as admins, which triggered further harassment. Other participants thought their cases were special due to going through complex home or health experiences.

> 'I am constantly crying. It's hard to get the police to take me seriously that it is still happening and to make matters worse it is to keep me silent and ruin my life as I was a victim of child sexual exploitation as a teenager, and if they keep this up, they still have power and control over me.' Participant B10

> 'He uses the fact I can be manic occasionally, depressed a lot, anxious a lot and in particular prone to psychosis (with delusions) as a tool to help keep him from being prosecuted.' Participant B11

Some complexity aspects were related to diversity elements and being from a minority or groups with 'less power', including ethnicity, gender and sexual diversity. In such cases, the participants perceived that targeting was complicated by additional elements of diversity to having a chronic condition or disability.

> 'When he found me, he was like, this is not just disabled but gay as well this is the one we are going to pick on. So when I woke up I had hundreds of messages from disablists homophobic libertines telling me I (..) I shouldn't be allowed to afford food so I would starve to death umm yeh a couple of disabled people in recent years have starved to death and these guys they found that idea hilarious' Participant B3

Most victims shared initially underestimating the situation; they thought it was not serious or it will end soon. However, the situation in all the cases worsened, reaching safety concerns. The participants thought that the experience might not be harmful and it would pass, while some attempted reasoning with the harassers.

> 'I thought in a couple of weeks it will go down it will be okay but then as this is going on I'm thinking actually it is not going any better' Participant B1

Subsequently, the victims realised that they were in danger, and most of them were concerned about facing the harasser in person, to be assaulted in their homes, especially when harassers could access the victim's address using the Internet or workplace information. The sense of danger affected victims' wellbeing, exacerbating fear and anticipation.

> 'So basically at the end of that conversation I said I can't help you, you need to seek professional help and at that stage that's the date when he first threatened me, I'd be meeting him some day and I'd regret what I have done' Participant B2

The ***struggle for support*** subtheme reflects how the complexity involved instrumental support channels and triggered further distress rather than resolving the situation. One channel of support was the police, but all victims who approached the police were dissatisfied and experienced subsequent stress. They perceived hostility, hate, ignorance, humiliation, not being taken seriously and lack of training. The victims were sometimes told to take time off social media or ignore the harassment as it was not perceived to be serious compared to physical assaults.

> 'I've already been on to them and they weren't always been helpful. Very always been not helpful, they were, I ended up really stressed though after talking to them' Participant B3

The role of Microsoft, online support groups admin and twitter administration was also limited and caused disappointment. The participants perceived that legal remedies and lawyers were not helpful, and there is a need to change the entire law, establishing a system whereby cyber-victimisation is treated as a physical assault.

> ‘Legal remedies are almost non-existent and the burden of proof is on the victim of ostracism/mobbing. I came to understand that complaint procedures are to get rid of the complaint not to resolve them. I feel if I had access to legal aid it may have helped somewhat for some of the issues. I was also refused advocacy which I believe may have helped bring some of the more serious issues to light.’ Participant B12

One participant experienced secondary cyber-victimisation when she attempted to seek support. This happened when the victim asked for help from the employer to stop the harasser. The victim was denied support and received an intimidating email that triggered panic and health consequences.

> ‘So (my employer) actually sent me a very threatening email, intimidating me with disciplinary, so they say if you do go around saying to people that you have been sexually harassed in our company and that someone from our company is stalking you we're going to give you a disciplinary, and that was really (..) I have, I have a copy of that email. I think it's even on my phone if you want to look at. […] When I got that e-mail. I felt really unwell because of my epilepsy and everything because I knew what had happened to me, you know, what I went through’ Participant B5

Victims support organisations were approached by a few participants, they were described as responsive and the participants felt that they were listened to, yet the advice was not always practical. However, some participants were not aware of the availability of victim support groups and organisations.

> ‘I spoke to a person on a helpline because I am sick of not being taken seriously, or perhaps the pain of my stalking is so great that I'm almost just trying to live with it by changing where I live, and not being online.’ Participant B10

With regards to healthcare professionals, some victims started seeing therapists and counsellors, however, this was not always helpful and some participants thought counselling made things worse.

> ‘My GP could only offer anti-depressants and referred me to a charity counselling service. Counselling made things worse’ Participant B6

The role of the GP as a supportive channel was also controversial. Most participants did not communicate the victimisation to their GPs, mainly due to embarrassment or because the victims did not perceive it as a health issue.

> ‘I was embarrassed to tell many people as I felt foolish that I had been manipulated online to revealing sufficient details about self to be identified offline. Usually very private, so shocked about events.’ Participant A 238

> ‘I’ve never told the GP about the cyberstalking and the stuff but I’ve got support from the Gp within the remit of their support. That is how far how it went. I’m really stubborn with that. Tomorrow is another day let’s see you tomorrow, that was it, that’s their level of support.’ Participant B8

> ‘I go to a GP, who, they are really sympathetic and everything but they don’t have the capability in order to know what to do really and they haven’t got the time to sit and talk so it’s a matter of going back to repeat prescriptions and hi how are you, you got any thoughts of harm? You got any thoughts of that, you got any thoughts of that, then I get my prescription, so it’s a tick list really, so I think for people like myself, and people who needs support for things like this., It's not there, is no sort of mental health support, there is no funding or anything so.’ Participant B7

The reasons to meet GPs were mainly for follow up, prescriptions, pain management or during the diagnosis process. Few participants thought that the GP was helpful through referring to counselling or online support. However, the majority of victims thought that despite experiencing health consequences, the GPs could not help them. Their reasons were either perceiving non-interest by the GPs or due to insufficient training.

> ‘At long last they have referred me for talking therapies! It would help if they took it seriously. Maybe pointed me to someone that can really help me. I feel terrible 24/7. No one really knows how to help I guess.’ Participant A 246

This also involved questioning the GPs response due to trust issues based on previous experiences with ‘traditional’ GPs. This was in cases where victims struggled to obtain diagnosis or when they were prescribed antidepressants after disclosing their cyber-victimisation experiences. Some participants blamed their GPs indirectly for being victimised, having been referred to online support where the victimisation happened, while others considered that a referral to online support was an approach to keep patients away from GPs.

> ‘I used the Internet forums for support and info about my problem. If GP had provided more info, I wouldn't have been on the Web!’ Participant A145

In addition, one participant thought that GPs access to his medical records was an obstacle in getting support, given that cyber-victimisation itself is not taken seriously and the victim has a chronic mental health condition.

Theme 5: Social Network Involvement

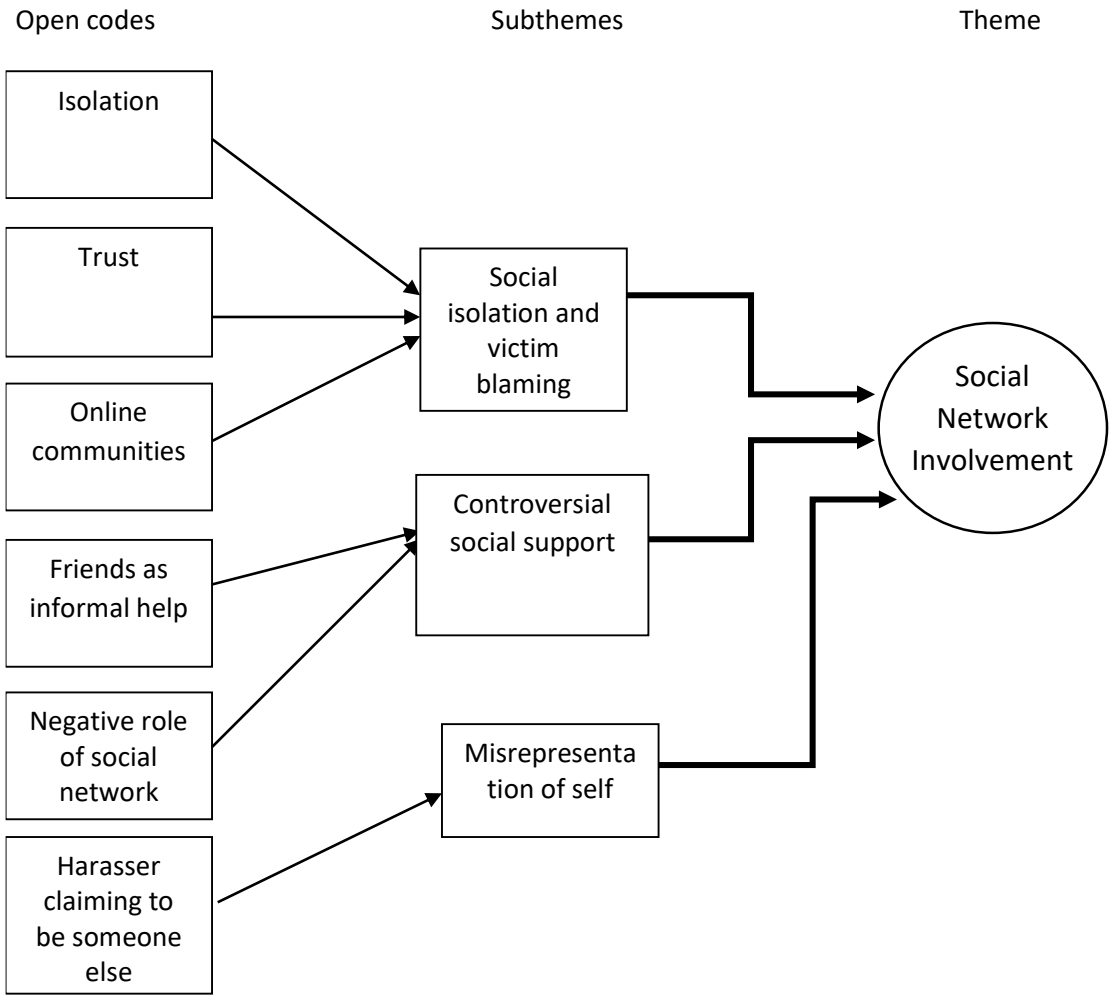

Figure 18. *The development of theme 5*

The involvement of the victims' social network in cyber-victimisation emerged as a major issue with variable aspects, which influenced health management. The social network here includes family, friends, online communities and other social interactions. This theme was common across both the interviews and the first data set. Three subthemes were identified: social isolation and victim blaming, controversial social support, and misrepresentation of self.

One of the prominent findings is ***the social isolation and victim blaming*** subtheme. It emerged from responses where the cyber-victimisation experiences became known to family and friends. The people involved became aware of the situation either through disclosure by the victim, witnessing the harassing actions, or being contacted by the harasser.

> ‘He has hacked into every form of communication, as stated above, and takes great delight in informing acquaintances regarding my misfortunes in life.’ Participant B11

> ‘Contacted friends and family on over 100 occasions via Twitter & Facebook Wrote articles & blogs with references to me & friends He only stalked me via Twitter because I don't use the other platforms’ Participant A169

Most victims experienced from social isolation afterwards; they described people disappearing and cutting them off. Some victims were faced with statements underestimating the harassment online, such as being funny or unrealistic.

> ‘I don’t have any support. I feel, to be honest people shy away from it, they they, it’s like victim blaming, do you know what I mean, you kind of brought it on yourself or they don’t know how to deal with it so they don’t deal with it they just cut you off’ Participant B2

Moreover, many victims lost trust in the people around them and in the society, primarily resulting from the social isolation described above. Subsequently, they expressed feeling betrayed, on their own, and no one cared about them. The other form of involvement was when some victims shared suspicions that people around them were used by the victim as data sources. It also happened involuntary when friends’ accounts were hacked. In both cases this resulted in further isolation and trust issues.

> ‘The people on twitter could see what was happening, and you know, none of my circle friends said you know I’m coming over and bringing take away’ Participant B3

The isolation and trust included friends in online communities too. When the harassment was witnessed by online friends their reactions were mostly passive. Few victims described positive online support. However, the isolation and trust issues affected the engagement with online support groups.

> ‘The stalking made me realise that not everyone in support groups are supportive’ Participant A5

> ‘Talked about it too much online and no one cared so made me feel more alone’ Participant A227

The ***controversial social support*** subtheme represents the variable roles played by the social network in cyber-victimisation. Friends were regarded as a form of informal support, but this was not always helpful. Some participants felt embarrassed because of their chronic condition, even when their friends were supportive, hence sharing the cyber-victimisation was a second challenge.

> ‘I don’t know really I suppose like when sometimes I be out to dinner with my friends and then they just eat what they want and don’t even have to think about it and then I’m thinking now I have to work out what I’m eating, am I gonna eat it all? […] I don’t like doing the blood test in front of my friends but not because they make me feel uncomfortable but because they are interested in it, so ‘’what you’re doing’’ “what’s your blood test today” “so what does that mean’’ ‘’what are you gonna do’’ ‘’ what insulin you’re gonna give’’ and although I know they are doing it because they care it actually makes me think I don’t want to make it in front of them because I don’t maybe don’t want to talk about it.’ Participant B1

Some participants involved their offline or online friends as means to check the harasser status or to validate their fears i.e., ensuring that the received messages contained distressing

materials and was perceived correctly. Therefore, the input from friends contributed to judging the situation by the victim, which in some cases underestimated the risk. Some family and friends attempted to contact the harasser, this happened either voluntarily by friends, which was sometimes perceived to be a wrong attempt to help the victim.

Some participants approached online groups to get health support, while some groups were very supportive, the harassment was perceived from other groups from friends themselves. This was an indirect form of harassment, where the friends intervened with the chronic condition diagnosis and triggered stress.

> 'I felt betrayed, as I had tried to be supportive to them in their journeys towards their diagnoses. Eventually I left the group […] I did have sleepless, tearful nights, wondering if these people were right - maybe I am lazy, maybe I do have thyroid problems.' Participant B4

In some cases, some people in the social network were also targeted as secondary victims. These were mainly friends, colleagues, or online friends. This situation put an enormous pressure on the victims, it added to the 'vulnerability' of the victims who became concerned about the safety of others too.

> 'I decided to stop all the attacks from her, I'm going to name her on my blog. I named her. She sent a message if this is not down by 3 o'clock I will tell your children. Which we haven't told the children, they just knew there was some upset, we didn't want the younger ones to know. Umm I was actually asleep when that text came through to me, and I woke up about ten past 3 in the afternoon so the text (..) I immediately took it down but it was too late, at 3 on the top she'd messaged all our children to say that I was writing this blog gave them the address and I've got to stop and everything. So you can now imagine your kids know everything, all the details, and how bad my mental health was and (…) that affected me quite a lot umm.' Participant B7

Another prominent finding emerged in the ***misrepresentation of self*** subtheme. The harassers in most situations used deception and claimed to be someone else to enter the victim's

network. The reasons were to get more information on the victims or to find a way to communicate after being frequently blocked. The means to represent self to the victim varied, one of the approaches was claiming to be healthcare professionals to get sensitive information, for example therapists or psychologists.

> ‘in March last year it was like umm the whole week it was over Christmas and that I have been talking to him umm he claims to be psychologist by the way, I have been talking to him umm he started telling me that... so he was sympathetic with me’ Participant B2

The medical condition and online health support also played a role in misrepresentation. One approach used was pretending to have the same medical condition to encourage the victims to share further information for use later for harassment purposes.

> ‘Someone was trying to gain information from me about my condition, pretending they were the same when it was clear they weren't’ Participant A97

Online health support groups were also misused. Some perceived harassment happened when salesmen of the ‘cures’ for conditions used their accounts to talk to the patients online. This triggered distress due to giving misleading information that added to the stress of coping and loss of trust in others. One participant perceived that alternative treatments and over-simplifying the health condition in online groups is a form of harassment that underestimates the impact and puts the blame on the individual.

> ‘… I did get a lot of ""think positive and this will cure your cancer"" rubbish on Facebook. I found it very, very hurtful. You can't be honest about how you feel, otherwise you are a ""victim"", not brace or ""amazing"" enough. So when my cancer comes back, and it DOES in oral cancer, that will be my own fault?! Another insult is the plethora of ""herbal"" remedies, or cannabis, or whatever - just think - I didn't need to have a 13 hour surgery: hemiglossectomy, modified radical neck dissection, temporary tracheotomy, PEG tube and 6 weeks of radiotherapy causing second degree burns to my face and neck and grade 4 mucositis with necrosis. No. I could have just have eaten some bloody parsley. Silly me.’ Participant A351

Some harassers were known to their victims, yet they claimed to be strangers. Other forms of misrepresentation were through claiming to be one of the victim's friends, which was used to gain more information on the victim or to get the physical address. This enforced the isolation of the victims.

> 'So he was talking to me, this friend of mine who speaks in Spanish, you know, he doesn't speak English at all and then all of a sudden the stalker he came as this person, and because of the conversation and I said you know you're not my friend. So I had to block this person, my friend, because he had hacked into his account' Participant B5

Most harassers also attempted to pretend being harassed by their own targets. Thus when the harassers communicated the victim's social network or with the support channels they acted as the victims, and caused further distress and struggle to get support as discussed in theme 4.

Theme 6: Disability Discrimination

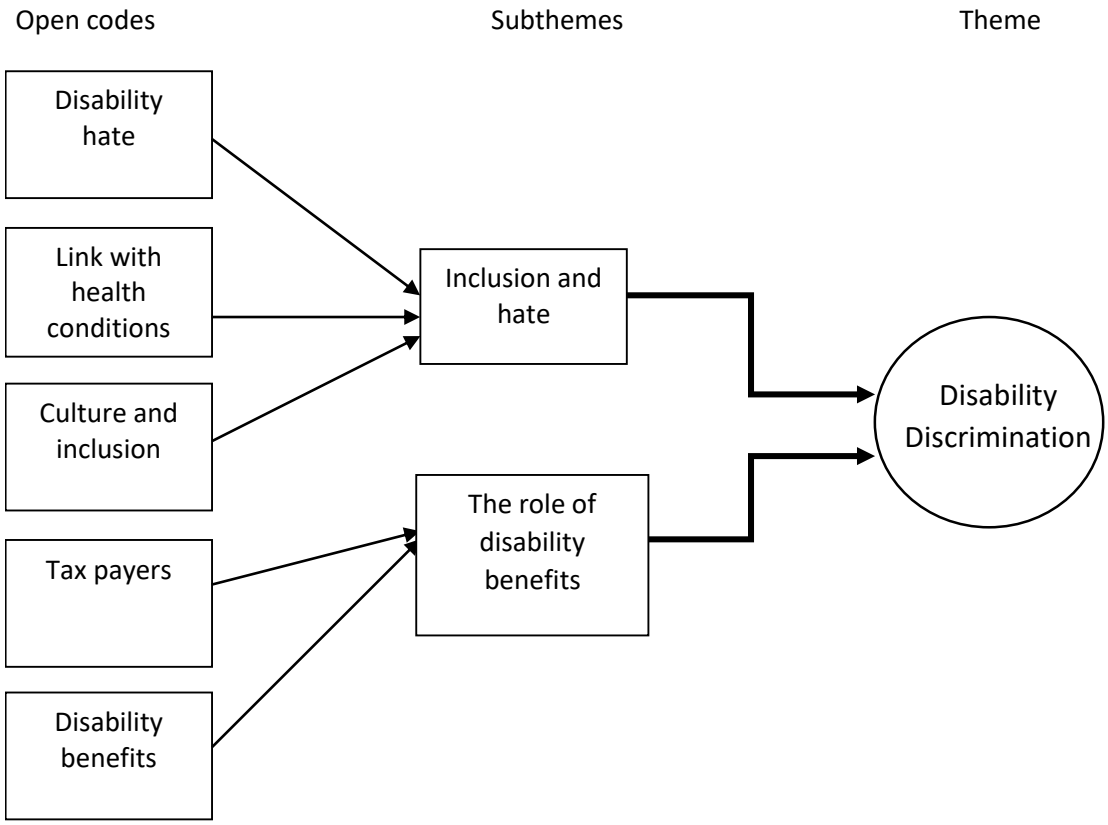

Figure 19. *The development of theme 6*

This theme emerged from the responses of participants living with disabilities. It centred on perceived disability discrimination, experiencing cyber-victimisation, underlying factors for prejudice, and the subsequent impact. The theme was observed in the interviews with the victims and was frequent across the first data set. Fighting disability discrimination was one of the factors encouraging activists in the field to participate in this study, hence the theme was present in these accounts compared to other victims. Two subthemes were identified: inclusion and hate, and the role of disability benefits.

The ***inclusion and hate*** subtheme is linked with the disability, medical condition and society. Hence, in this subtheme, victims were faced with abusive online behaviour that was perceived to be underlined by disability prejudice. Discrimination and targeting were experienced, ranging from offensive words to organised campaigns. The victims were subjected to offensive language, usually by multiple harassers, and in some cases, participants were told to kill themselves or they should be beaten or starve to death. Most participants who experienced this called it a hate incident/crime.

> 'You know when you know wake up in the morning and umm your twitter's notifications has got hundreds of messages from at least two dozens different people because umm one person who has got 7000 twitter followers has decided hey let's abuse this disabled person.' Participant B3

The medical condition was linked to disability discrimination in several ways. The medical condition was used when the harassers tried to find the victim's medical information online and then used it to abuse the victims. Another form of abuse was when the harassers did not find information on physical illnesses online, they used mental illnesses to claim that these disabled victims were not genuinely disabled. Some participants experienced these comments when they used online shopping services, and this abuse affected how they dealt with their physical impairments afterward. One participant perceived discrimination in the workplace when the harasser used the sick leave and payslip to get to the victim or to block promotion.

> 'He's basically ruined my job, you know, going back then he stopped me from getting a promotion. I was doing this job informally for one year and I had epileptic seizures in July, I stayed out of work for one month and when I came back they hired someone else to do my job […] they said we did not invite you to the interview because you were off sick with epilepsy, and this is discrimination' Participant B5

The medical legitimisation of the disabling health condition to the public was one of the prominent findings. Some victims experienced cyber abuse because of the relative invisibility of their conditions i.e., they were harassed because of not looking physically disabled, so they had to legitimise their conditions to 'others'.

> 'We don't produce as such, we have time off more than most of people, we need more support which costs money. Nobody is arguing about the assessments. One size fits all. What is most frustrating is that chronic illness is never ever mentioned, it's never mentioned at most of people on have a chronic illness, it's not a physical disability that puts them on a wheelchair, we need to talk about that and also need to talk about the fact that most of the disabilities are hidden disabilities we need to have conversation on that.' Participant B8

To overcome this, when the victims had multiple conditions, the apparent physical impairments were used to legitimise the disability to the public to avoid harassment. Another approach to avoid harassment was through creating online identities in which the disability is incorporated. For example, one victim with ME, memory disturbance and spinal injury adopted both tactics to avoid harassment.

> 'This is made much more difficult because many people do not believe in ME, so accusations of being lazy, or having something else wrong with me that I just haven't 'bothered' to get better from. I tend to use the spinal injury as a cover for my ME - 'Sorry, I'm in a lot of pain from my back - can't concentrate today' Participant B4

> 'I have cultivated a scatter brained persona and nickname of 'Dizzy' and cover up my problems with humour. For that reason, I do prefer to interact online, as it is easier to sit and wait for the right word to come to mind, or rewrite a sentence without it.' Participant B4

When this participant was asked about how she created her online persona, she explained how the persona covered for her symptoms.

> ‘I think the Dizzy persona sort of created itself! […] I then started using it to cover up, saying things like, 'Dizzy by name 'cos dizzy by nature', or 'Well, what do you expect from someone called Dizzy?' Saying something like that would make anyone who reacted badly appear rather churlish. However, that's a nickname I keep for friends and lightweight social interactions. I am still very much Mrs xxx when I need to be serious about something. In that sort of scenario I would play the Disability card -- 'I have a medical condition which means I struggle with speech, memory, energy levels, it is essential that, etc etc. All that is in real life, tho' - online, no-one can tell! Emails can be worked on bit by bit.’ Participant B4

The participants blamed the surrounding context for victimisation, using both “culture” and to less extent “society” terms. This explanation was overwhelmingly present in victims’ explanations of the cyber-victimisation phenomenon. Disabled participants who experienced cyber-victimisation perceived that such hate incidents and the medical stereotyping of disability were underlined by cultural discrimination issue, and that the surrounding society is unwelcoming to chronic illness and disability.

> ‘Online and cyber bullying is just the tip of the discrimination people like me face. The blame culture in the UK currently is such that ageing and health conditions have become socially unacceptable in all aspects of life.’ Participant A168

> ‘one of the things that particularly rolled them up is that I can’t carry shopping from car so I use online delivery service umm and they thought that was absolutely disgusting, someone living on claiming benefits have their shopping delivered which is abusing a person for having shopping delivered because they can’t carry it in and delivery is more expensive than going to LIDL is absolutely no different from bullying a disabled person for getting a wheel chair which is more expensive than shoes but yeh that’s the kind of people they are.’ Participant B3

This was especially shared by participants with mental health or invisible disabilities; these participants faced prejudice due to not looking ill. However, it was also experienced by participants living with chronic conditions like diabetes.

> ‘In some ways because although I am proud to be who I am because of society perceptions of mental illness people often mentally have a go at you with things like 'you are such a drama queen' or being told that I fake it or I am attention seeking. Very few people know what it's like to live life with my illness and very few people appreciate it and how hard it is so I often get negativity not just online but in the streets. Mental illness comes with a huge stigma’ Participant A375

Such discrimination left the victims with a sense of exclusion; the surrounding culture failed to include them and was also extended to the online context. Twitter users who were disabled were labelled as lazy and reliant on others. Additionally, they felt excluded because other users in their network were passive towards this harassment. The policy in Twitter at the ti,e of harassment was not-protective either. This sense of exclusion went beyond social media to a general feeling of abuse by the government.

> ‘I don't admit to being a diabetic because of the current culture of blame attributed to those of us with this condition. The common assumption of many is that type ll diabetes is self-inflicted, that we are overweight, lazy and a preventable drain on the NHS. On the rare occasions that I admit to the disease I am often met with the comment " but you are not fat" by those who know what I look like. This assumption of self-infliction is prevalent even among health care professionals. Online I have been referred to as a "fat cow" or " idle drain on our taxes" by those who have never seen me or know anything about me, other than my admission that I'm diabetic. […] Like many I keep my medical conditions, their treatment, complications and the negative impact they have had on my life to myself […] I have had comments about being a lazy scrounger with a fake illness after commenting on a couple of social media pages at how I feel and deal with my health’ Participant A 401

A negative instant emerged by one participant who was involved in administering an online support group for people with disabilities. In this incident both the harasser and the target were disabled people participating in that support group. The harassment started because of differences in opinions on how to react to disability cuts.

> ‘We get lots of hate towards individual campaigners, and we don’t stand because we give instructions. That’s a challenge when you are administrating a group. You become a target when you tell them off being a racist or ablest, and that sort of things […] We are just used to it, we just get so much abuse online, just for standing up for what our believe is like, and if people disagree with you, you become a target, and I don’t understand the mentality behind it’ Participant B8

The ***role of disability benefits*** subtheme emerged from victims' experiences of abuse that was linked to financial causes, mainly victims relying on disability benefits and tax paying harassers. The victims perceived that their harassers' motive was related to tax paying because they believe that disabled people are a waste of money and could even be the cause of financial crisis. Hence, harassers' comments included discouraging people from online shopping because it is more expensive, or included abusive threats that people with disabilities should be beaten to discourage them from claiming benefits. Accordingly, the participants who were receiving disability benefits were frequently harassed online.

> 'Abused me and others on politics forum and every time the troll was banned it would come back under another name. It even created a hate blog claiming that most disabled people on benefits are scroungers and frauds.' Participant A152

The previously discussed legitimisation of the disabling condition, by the medical confirmation of the condition through clinical assessment, interacted with applying for disability benefits in this subtheme. This is because some working disabled people who were cyber-victimised had to give up their jobs and apply for benefits. However, these were stuck between support channels that were not adequately trained to understand the impact of cyber-victimisation as discussed in theme 4. During the interview, one participant left her work and applied for benefits due to the worsening of mental and physical health following cyber-victimisation.

> 'They give me a medical certificate because I'm having to be paid benefits now because I'm not working. So I've applied to employment department allowance and that's a big change because my payment was quite good.' Participant B5

However, later on upon follow up, the assessment did not consider the impact of cyber-victimisation in this case and the victim who was facing health complications was denied disability support due to the unconvincing grounds of cyber-victimisation.

Despite that, even in the cases where disability benefits were granted, most victims faced difficult circumstances when they experienced cyber-victimisation. They found that the support was not enough to afford housing, and some had to give up work secondary to victimisation. This left the particpants with difficult living situations that affected their mental health, physical health and families.

> ‘I have gone from a £350 - £400/day consultant to living on benefits. One of my ex-partners aborted our unborn child to get away from me when it started to become clear supporting her would be an issue’ Participant B12

> ‘I was homeless for a while because the council wanted to put me into a flat which, even with Housing Benefit, I couldn't afford.’ Participant B6

The role of disability benefits was underlined by the tax paying and the political context. The victims were faced with offensive comments because the harassers considered them a waste of the tax being paid to the government. The participants blamed the media and political context for promoting such hostile thoughts that mediated the harassment.

> ‘I mean it’s, you can put it in the current political context in Britain so for 10 years now we have this constant stream of misinformation from the government to impress that all disabled people are a waste of tax based many, that we cost a fortune of benefits and offer no value to the society, you know so we must be, you have a life line cut off and be left to die umm and that had really fuelled online abuse so yah I mean for years now a lot of disabled people who had been in a situation where you know periodically umm you will get talking like oh she should have been killed at birth to save the tax payer money and people like me need to be beaten to discourage us from claiming benefit umm and so and that’s not an experience only to me, you know all disabled people get it. It constantly come from the government and press that disabled people are this huge waste of money umm that our continued existence is a financial burden on the country, that disabled people claiming benefit is responsible for the financial crisis about eight years ago and so you know people hear that from the Politian and read that

> in daily mail so they go out and start looking for disabled people to say you know you are just a waste of money.' Participant B3

Subsequently, another form of cyber-victimisation was the malicious calls to the disability benefits hotline. In such cases, the harassers contacted the hotline to claim that this person was pretending to be disabled. This affected the victims because their support was suspended to prove innocence. This period of suspension caused much distress to the victims and perceived satisfaction to the harassers.

4.4 GP results

A total of 14 short written interviews were conducted with GPs in the UK. The age range of participating GPs was 32 to 62 with a mean of 43.7 (SD = 8.91). The majority 10 (71.43%) were female doctors and 4 (28.47%) were males. Most of them 11 (84.62%) were from White ethnic backgrounds, while the rest 2 (15.4%) were from Asian backgrounds. The years of clinical experience ranged between 8 to 35 years, with a mean of 19.2 (SD = 8.07). All participants had worked as GPs in the UK, with most of them working as GPs at the time of data collection, while two preferred not to say their current status. A total of seven GPs directed their patients to online health forums. The GPs were working in different geographical areas as detailed in Table 39.

The GPs were provided with the definition of cyber-victimisation in this study as 'negative online experiences characterised by repeated unwanted contact via the Internet/electronic communication such as email, chartroom, online forum, social network, phone message or call, that causes fear or distress'. Unwanted contact includes online/cyber-harassment, cyberstalking, online trolling, cyberbullying, online discrimination or online disability hate incidents. GPs were then asked whether they encountered patients with chronic conditions who communicated such

experiences. Four GPs (28.6%) had encountered patients having chronic conditions and complaining from cyber-victimisation. They reported having one to more than five patients experienced this issue. GPs were asked about these encounters and about their medical knowledge on cyber-victimisation as explained in section 3.4.3 and Appendix 20. Due to the limited time availability of GPs in the UK (as discussed in section 2.3.4), to successfully recruit GPs the required answers were brief to cover the main points and cross-check them with the victims' results. However, the responses from GPs shared similar patterns and four overarching themes emerged from the analysis of the qualitative data.

Table 39. *The demographic characteristics of the participating GPs and the main themes emerged from each interview*

GP	Age	Gender	Ethnicity	Years of clinical experience	Region	Patients reported cyber-victimisation	Referral to online health support	Main themes
GP1	46	female	N/A	20	UK	No	N/A	Individual variations
GP2	32	female	White	8	UK-Greater Manchester	Yes- no details provided	N/A	Individual variations
GP3	62	male	White	35	UK-West midlands	No	No	Individual variations
GP4	53	male	Asian	30	UK	No	No	Individual variation Mental Health (-ve instance)
GP5	37	female	White	14	UK-West Sussex	No	No	Individual variation

GP6	59	female	White	32	UK-Lancashire	No	Yes	• Serious impact on health conditions • Impact on online health support
GP7	40	female	White	15	UK-Hampshire	No	Yes	Serious impact on health conditions
GP8	43	female	White	20	UK-West Yorkshire	Yes- one victim presented with depression-experienced mental health complications and was advised to contact police but refused	Yes	Impact on mental health
GP9	36	male	White	14	England	Yes-one victim with mental health condition cyberstalked by ex-partner with mental health complications	Yes	• Serious impact on health conditions • Impact on mental health • Individual variation • Online health support
GP10	37	female	White	15	UK-Surrey	No	Yes	• Serious impact on health conditions • Impact on mental health

GP11	47	male	Asian	22	UK	No	No	• Serious impact on health conditions • Impact on mental health • Individual variation •
GP12	48	female	White	23	England	No		• Individual variation • Online support
GP13	37	female	White	13	England	No		• Impact on mental health • Individual variation • Online health support
GP14	35	female	White	9	England	Yes- more than 5 patients with different health problems and mental health consequence. Advice about mental health was given.	Yes	• Serious impact on health conditions • Impact on mental health • Individual variation • Online health support

GP theme 1: Serious Impact on health conditions

Most of the participating GPs perceived cyber-victimisation as a serious issue. Subsequently, they recognised its potentially significant influence on the health and wellbeing of victims. GPs emphasised that this impact in general can potentially worsen the existing chronic condition.

> ‘Any cyber-victimisation is very serious no matter whom it is aimed at’ GP6

> ‘Any victimisation is serious, doesn't matter what the source is’ GP7

With regards to management and coping, most GPs thought that cyber-victimisation undermines the self-management of their patients, such as affecting behaviour and adherence to the required daily management. The social-related impact was also mentioned by one GP.

> ‘It can significantly impact on self-worth, self-confidence and wellbeing and hence on behaviours related to worsening or improving their condition.’ GP8

GP theme 2: Impact on mental health

The majority of GPs perceived that the main impact of cyber-victimisation was mental health related, either non-specific or specific. Non-specific mental impact was perceived when GPs referred to distress, psychological wellbeing or mental health.

> ‘Potentially extremely distressing and damaging for vulnerable individuals’ GP13

Some GPs recognised more specific mental health impact related to cyber-victimisation. These cases included mainly depression and anxiety. One GP added panic attacks and agoraphobia based on personal experiences as will be discussed in theme 3.

> ‘All this leads to a breakdown with severe anxiety, panic attacks and agoraphobic tendencies.’ GP5

GP theme 3: Individual variations

The responses of GPs reflected individual variations in perceiving the impact of cyber-victimisation. Indeed, GPs who had already encountered patients who had experienced online abuse were more sympathetic and expressed some understanding on the impact. Their attempts to help focused on general advice or advice about domestic abuse, without specific advice on cyber abuse. Some recommended contacting the police, but the victim was not keen because of a previous negative experience with the police. On a more negative note, one GP misunderstood the study and thought the aim was to increase the workload on GPs.

> ‘It's limited times that my vulnerable patients mention this, but it may be more prevalent as I don't ask.’ GP9

> ‘Please do not add this non-medical problem to GP workload. We have enough to do already. There is no reason why GP should look at peoples online problems.’ GP 4

Some GPs, despite sharing concerns about the general impact of cyber-victimisation, considered themselves unaware about its impact on self-management. This perception was underlined by their lack of practical experience in encountering patients with cyber-victimisation experiences.

> ‘I have no experience of encountering this through work’ GP5

> ‘I am not aware of any impact from my experience, although can see the potential for this’ GP13

In this group, few GPs seemed less concerned about cyber-victimisation. This was due to underestimation of what happens online and thinking it could be solved by avoiding being online.

> ‘Switch it off’ GP3

Another variation emerged from the group of GPs, in addition to appreciating the impact of cyber-victimisation, considering the referral system and the wider picture, they thought that cyber-victimisation was better addressed by the police and that GPs should be able to direct victims to the proper authorities.

> ‘Often cyber-victimisations is part of a wider picture. It is rarely the only problems but represents another facet in the ways in which vulnerable patient groups can be harmed.’ GP14

GP theme 4: Impact on the use of online health forums

This theme emerged from GPs responses in questions specific to online health forum use, these were added after phase one input in piloting (Appendix 15). Most GPs who reported that they often referred their patients to online health groups explained that it helped in providing useful information for specific conditions. Some GPs reported having good experience with online health forums, while other GPs perceived some risk factors, including the inaccuracy of online information, the website’s agenda, salesmen and administration controlling the website.

> ‘Generally positive, but concerns expressed about accuracy of information available’ GP13

> ‘Negative regarding forums they had found themselves. Positive about forums I had directed them to. Issues with the former around lack of moderation and inaccurate content, often American.’ GP14

> ‘Generally positive though I always give people advice when looking at anything on line to keep aware of who they are communicating with and what their agenda and expertise is’ GP8

Furthermore, few GPs linked online health support to cyber-victimisation, this included losing the chance to use online support as a consequence to cyber-victimisation.

> ‘I would imagine it deters them from using on-line facilities’ GP6

They also attempted to explain the cyber-victimisation through the use of online health support, such as online behaviour and the Internet as a means of anonymous communication. One GP was specific to people with intellectual disabilities and how using these websites can trigger harassment.

> ‘I think people feel removed from their online comments & so write things they'd never say face to face …Also meaning can be difficult to convey in the written word.’ GP12

> ‘I think it is harder for other members of the public to know when someone has a learning disability if using a forum. When comments are not fitting the general theme of a thread or perhaps the comments make less sense or are more inflammatory, then I am sure the public react in a way that assumes that person is as able bodied and minded as themselves. It does not explain continued victimisation or bullying by one person as by then, I'm more sure they are aware of what they are doing.’ GP9

4.5 Employing the results for health promotion

The second aim of this study (section 1.2.2) was to employ the results from this research to increase awareness and improve the wellbeing of people with chronic conditions who go through the experience of cyber-victimisation. The results from the participants in sections (4.2), (4.3), (4.4) and the input from the GPs in section (4.5) were compiled in one health promotion design

for further development and dissemination. This section describes how the results presented in this chapter were summarised in a health promotion design. This will be by providing a supportive background on health promotion in section (4.5.1), and the subsequent development of the design in section (4.5.2). The results from disseminating the design to gatekeepers and participants will be addressed in Chapter 6, in the dissemination section (6.3.2).

4.5.1 Supportive background to plan health promotion

Health promotion is a relatively new area of public health. It was introduced to a biomedically-dominated field after the1986 launch of the Ottawa Charter for Health Promotion at the first International Health Promotion Conference (World Health Organization, 1986). Health promotion was defined as a 'process of enabling people to increase control over, and to improve, their health' (World Health Organization, 1986, p.1). This definition is still the most commonly used and universally recognised (Laverack, 2014a). Accordingly, the concept of promoting health is a part of public health rooted in the process of creating the conditions for people to improve their wellbeing, and this involves both educational aspects and community involvement (Jackson, 2014). It focuses on empowerment rather than behaviour change, which makes it a suitable approach to adopt with marginalised groups (Laverack, 2014b).

In the early stages of this study, the aim was to employ the findings for health promotion due to the impact of cyber-victimisation on the wellbeing of people with long-term conditions (section 2.3.3 and section 2.4.3.5), the marginalisation of people with disabilities (section 2.2.4) and people who experience cyber-victimisation (section 2.3.4). In addition, enabling people to control their own wellbeing is a crucial aspect of the self-management of chronic conditions, as discussed in section 2.2.2. As the research progressed, it emerged that almost one in every three people with long-term conditions experienced cyber-victimisation (section 2.2). The findings

helped in uncovering the multi-level, complex impact of cyber-victimisation on people with long-term conditions, which included the impact on their physical wellbeing (theme 1), the impact on their mental wellbeing (theme 2), social network factors (theme 5), and other contributing factors related to instrumental channels, health support, living conditions, employment, financial factors and public policy (themes 3, 4 and 6). These findings, in sections 4.2, 4.3 and 4.4, and the reflection on the recruitment process (section 3.6) helped in directing the health promotion aspect of this study by identifying the short term audience for awareness raising in a harm-reduction approach, and interested support groups as potential partners and influencers.

In the Ottawa Charter, the five health promotion action areas were identified: building public health policy; creating supportive environments; strengthening community action; developing personal skills; and reorienting health services (World Health Organization, 1986). The Ottawa Charter was followed by several charters and statements with an interval of two to three years (World Health Organisation, 2009). In 2005, the Bangkok Charter for Health Promotion in a Globalized World was seen as the first attempt to revise the Ottawa Charter to extend the definition and address the wider determinants of health (Laverack, 2014a). The following paragraphs discuss the five action areas in health promotion in relation to this study.

First, building public health policy involves promoting health beyond healthcare to be a priority on the agenda of policy makers in all sectors by considering the health consequences of their decisions, for example, taxation (World Health Organization, 2009). This action is relevant to theme 6 on disability discrimination, when the participants faced cuts in disability benefits on top of being targeted, which resulted in further impact on their wellbeing due directly to distress, or indirectly to financial impact. It is also relevant to theme 4, when the participants struggled to get support from instrumental support channels such as the police, which caused further distress. Consequently, compiling the findings from this research in a health promotion design could assist

activists, disability hate crime campaigners and the supportive groups who were involved in this study, to influence public policy to prevent such harm.

Second, creating supportive environments recognises the complexity of societies, changes of patterns in life, work, and the link between people and their environment. This This action is relevant to themes 3 and 4 where the participants faced complex situations and disruption to their personal lives, work and living conditions. This action also acknowledges the growing role of technology in reshaping the environment, which must be followed by action to ensure positive benefit to public health (World Health Organization, 2009). This is relevant to this study where the online environment in theme 5 posed health risks to people.

Third, strengthening community action focuses on health promotion through effective decision making and setting priorities in the community. This includes individuals taking ownership of their destinies and being empowered (World Health Organization, 2009). This action is relevant to theme 5 in the findings which involves the social network of the participants, including online communities. Such work draws on resources in the community to enhance self-help and social support (World Health Organization, 2009). This aspect was important to the planning of health promotion in this research due to the reflection on the recruitment process (section 3.6) that uncovered the essential role of online patient and victim support groups, and the role of self-advocacy to initiate change. Social groups such as advocacy groups and special interests groups have an irreplaceable role in influencing public policies to support health (Wold and Samdal, 2012), and this will be further discussed below. Thus, the tool described in the next section was shared mainly with these communities, who were described as gatekeepers in this study, to support this action in the longer term. This action also includes the role of the determinants of health, which are acknowledged as contributing factors to health and wellbeing (World Health

Organization, 2009). The social determinants of health related to this study are stress, as emerged in theme 2, social exclusion in theme 5, and unemployment in theme 4.

It is acknowledged that empowering marginalised groups requires careful consideration of the context. For example, Owens (2011) examined oral health promotion among children living with disabilities as a marginalised group in Ireland, and highlighted the importance of contextualising health promotion interventions for effective health promotion. Therefore, understanding the context is also consistent with this study because it examined the scope of cyber-victimisation among a marginalised group in the UK, an issue which was not addressed in the UK before (Alhaboby et al., 2016). However, further context-specific work is required. This research also prioritised the qualitative input to understand participants' experiences, which informed subsequent health promotion, as will be discussed in section 4.5.2.

Fourth, developing personal skills includes health promotion through personal and social development by providing information, education for health, and increasing the options available to people to exercise more control over their own health. This also includes preparing people to learn and cope with life, chronic conditions and injuries (World Health Organization, 2009). This action is relevant to themes 1 and 2, which reflected the physical and mental impact of cyber-victimisation upon people with long-term conditions. Therefore, the health promotion design included these findings as a step of awareness raising, through supportive communites, to inform people who are going through this experience on this risk, especially that most of the partcipants underestimated this impact and only realised its effects on them at later stages, as is demonstrated in theme 1 (section 4.3). Developing personal skills is achieved through educational, professional, commercial and voluntary bodies (World Health Organization, 2009). Health education is only one aspect of health promotion; it includes raising awareness and providing individuals with information on how to improve their health and change health-related

behaviour (Gottwald and Goodman-Brown, 2012). Consequently, this study includes an educational aspect through sharing the results in a health promotion design. However, it goes beyond health education because it identified cyber-victimisation of people with chronic conditions as a public health concern, and the design was shared with the gatekeepers who represent the interested supportive communities, as a first step towards the involvement of the public, and influencing the role of healthcare professionals and policy. Such close work with the gatekeepers led to further impact by the use of the findings to inform the UK legislation on criminalising cyber-abuse of people with long-term conditions (Parliament, 2018).

Fifth, reorienting health services is mainly achieved by sharing the responsibility for health promotion among individuals, communities, healthcare professionals, health services and the government. It was recognised that health professionals, particularly in primary care, have an important role in health promotion (World Health Organization, 2009). This is relevant to theme 4 in this study, where the participants either did not share their experiences with their GPs, or met with mixed responses when they sought support from their GPs (section 4.3). It is also relevant to the themes identified from the GPs' input to this study, which confirmed the impact shared by the participants but also showed subjective variations (section 4.4). Thus, according to this action, the role of healthcare involves a change in the attitudes and organisation of health services, to focus on the total needs of the individual as a whole person. Consequently, the health promotion design in this study was used to reflect the input from the GPs to raise awareness among people with long-term conditions. Due to the GPs' variable responses in this study, they were not considered as a primary target for the design, because involving GPs to support people who experience cyber-victimisation requires training and change in policies.

Considering the health promotion actions discussed above, the findings of this study reflected a multi-faceted complex impact on people with long-term conditions that is located in

most of these actions and requires collaborative work. This aligns with the argument by Wold and Samdal (2012), which acknowledges the multiple pathways to health promotion that are linked systematically and require multidisciplinary work. However, tackling all of these factors influencing the health of the participants is a long-term process. Thus, the study included the short term action through a health promotion design, as a means to reduce harm to people who already experienced cyber-victimisation, in addition to disseminating it to supportive communities to influence action and prevention in the longer term.

Health promotion combines diverse but complementary methods or approaches including communication, education, legislation, organisational change, and community development (World Health Organization, 2009). Thus, it is a partnership between the individual, professionals and policy makers (Gottwald and Goodman-Brown, 2012). The three important roles for health promoters were described in the Ottawa Charter; these were: advocating, mediating and enabling (World Health Organisation, 2009). Advocacy is a major strategy in health promotion; it comprises a combination of individual and social actions towards a health goal. Mediation, as a strategy, is a process through which the different interests of individuals, communities, and sectors are co-ordinated in ways that promote and protect health. Enabling as the third strategy involves taking actions and mobilising resources to address differences in health (World Health Organization, 2009). To tackle the impact of cyber-victimisation at this stage, supporting particular causes or interest groups is achieved mainly through advocacy, which involves people acting on behalf of themselves or others to argue a position and to influence the outcome of decisions (Laverack, 2014a). There are several forms of advocacy, which include: health advocacy, through enhancing community health and policy initiatives; media advocacy, through the use of mass media; collective advocacy, when groups or organisations arrange campaigns for their members; peer advocacy, when a person agrees to act on behalf of another; self-advocacy, when individuals or

groups share the same concerns or act on their own behalf; and legal advocacy, when a legally qualified person is employed to act on behalf of others (Laverack, 2014a). In practice, the different forms of advocacy overlap. In this study, self-advocacy and peer-advocacy, through involving the participants and supportive communities, were adopted to help in using the findings to prevent complications at the individual level and promote wellbeing through the gatekeepers as support groups.

Laverack (2014a) suggested there are five common approaches in health promotion, but most health promotion activities would use more than one of these approaches. The first one is asset-based community development, centred on building on the strengths of a particular community. In this research, people who experienced cyber-victimisation were mostly isolated (theme 5). Thus, this asset-based approach could be of future interest to support people with long-term conditions due to the presence of supportive online communities (Alhaboby et al., 2017a). The second approach is harm reduction, which is based on reducing the harmful consequences of behaviours or events (Ritter and Cameron, 2006). This approach aims to work with people, without victim-blaming, to achieve terms of health promotion in their context in a specific situation (Laverack, 2014a). It also acknowledges the role of social support (Ritter and Cameron, 2006). Therefore, this approach was consistent with this research and a fit within the theoretical framework, to support the self-management along with acknowledging the role of social support (section 2.5.3). The third approach in health promotion is via the innovative use of online communities and technology (Laverack, 2014a). It is based on sharing health information with peers. Peer support (Coulson, 2015) and online communities (Alhaboby et al., 2017a) are integral components of this research, and this approach was adopted to disseminate the health promotion design. The other two documented approaches for health promotion are lobbying, through influencing official decisions, and using moral principles to change health practices (Laverack,

2014a). However, these two approaches are not relevant to this study at this stage. Accordingly, the health promotion in this study adopted a harm-reduction approach, with an element of innovative online communication, proposing the future use of community assets.

Additionally, health promotion theories are based on the individuals, the communities, and policies (Cragg, Davies and Macdowall, 2013). One approach is strategic theory-based, ranging from purely medical methods focusing on disease prevention to a lifestyle approach tackling inequalities (Cragg, Davies and Macdowall, 2013). However, the medical approach focuses on the treatment or prevention of particular health conditions (Gottwald and Goodman-Brown, 2012), thus it does not recognise the wider determinants of health that were found to be critical to this study. The behaviour change aspect of this approach encourages people to change their behaviour. It is to be noted that part of this strategic approach is educational, raising awareness among people and helping them reach informed decisions (Cragg, Davies and Macdowall, 2013). This aspect supports using the findings from this study to tackle the second and third actions of health promotion. However, as explained above, this study goes beyond health education. Furthermore, an empowerment approach focuses on individuals' perspective to identify their own health issues to address them (Gottwald and Goodman-Brown, 2012). Thus, the educational aspect, supported by the advocacy strategy, is consistent with this research and with the methods discussed above. Accordingly, the health promotion intervention in this study was mainly to increase awareness of the scope and impact of cyber-victimisation of people with chronic conditions to prevent health complications, enable them to take control and influence others. This was achieved by illustrating, in a health promotion design, that people who go through this experience are not alone, encouraging them to understand the experience, its impact, get support and initiate change to promote their wellbeing, as will be explained in the next section.

4.5.2 The preliminary design for raising awareness

Health promotion is based on both context and theory, and it therefore brings art and science together (Laverack, 2014a), the approach adopted in this study. Graphic design was traditionally used in communicating medical research (Duke et al., 2015). An infographic approach, using graphs or figures, was mainly used in the literature to communicate research results, however, this is a potential approach to communicate for health promotion as well (Ninomiya, 2017). The infographic approach was used in research in Canada to promote health in relation to foetal alcohol syndrome (FAS), and it was found beneficial for communication, especially with diverse audiences (Ninomiya, 2017). Additionally, infographic methods are increasingly used in communicating research findings, and they are interesting to the audience in health areas (Featherstone, 2014). The health promotion design here was developed following the study of posters available on the NHS website, Castle Street Surgery, and Luton and Dunstable Hospital, in addition to examining the literature (Ninomiya, 2017). The design was disseminated in the form of a poster (Appendix 27) and a booklet (Appendix 28) to be shared with people who experienced cyber-victimisation, and the gatekeepers, due to their role as supporters and influencers. It consisted of a central area carrying the logo and the two main questions in the survey, which related to having a long-term condition and being cyber-victimised. The central logo in the design was developed to portray Wi-Fi and the role of online communication, health and the London Underground sign to indicate the UK as a context.

The design then follows a circle, which is the pattern of cyber-victimisation as shared by the participants in theme 4. If the answer to the two main questions was yes, then two theme-based stories were presented, one story on cyber-victimisation and chronic conditions, the other on cyber-victimisation of people with disability due to the significance of this finding (section 4.2.6). The stories were built in accordance with the participants' accounts; the sentences were coloured

and the keys to the colours used reflect the themes from the data (section 4.3). The experience from the participants' perspective is an important aspect of this research that was rarely addressed previously in the area of health promotion (Gubrium, 2009; Raphael, 2000). Thus, direct quotations from people who experienced cyber-victimisation were used to reflect the impact of cyber-victimisation, and to help with understanding of themes from the victim's perspective.

After establishing the impact of cyber-victimisation, the role of the GP was introduced to the circle in the form of themes and direct quotations. This was necessary for raising awareness to strengthen the presence of impact from healthcare professionals and encourage people to communicate their health issues secondary to cyber-victimisation without embarrassment (section 4.5). The study was briefly described, followed by the main statistics and contact details for further information. However, there had to be a way to show people who go through this experience that the circle is not inevitable; this was achieved by the key message and support. The support slide was kept blank at the beginning. The design was sent to the participants and support groups for their input to improve it (Appendix 26). These gatekeepers were also asked whether they wanted their contact information to be shared to support people who go through this experience or use it in their campaigns to support this issue. The input of the gatekeepers and the participants was incorporated in the design and discussed as part of the dissemination of this study in section 6.3.2.

4.6 Summary of results

In the survey, the majority of participants were females, from white ethnic backgrounds, and aged 18-65 years. However, the sample was diverse across all ages, ethnicities and other diversity elements. Those participants reported a wide range of 340 chronic conditions over different physiological systems. They also reported variable self-management plans. Most had

multiple co-morbidities and their daily-lives were disrupted by the diagnoses of their conditions. Almost one in every two people in the sample experienced cyber-victimisation, with most participants reporting fear and distress. More than half of the victims reported that cyber-victimisation had influenced their self-management plans for their chronic conditions. The highest impact included lifestyle changes, followed by impact on medication use and follow up. Almost a quarter of the victims spoke to their GPs about this experience, however, they received varied responses. Cyber-victimisation was not found to be related to age or gender. However, one of the prominent findings is the statistically significant relationship between cyber-victimisation and self-reported disability. In total, 102 participants had a self-reported disability, comprising the majority of the victims. Fear and long duration were also significantly associated with cyber-victimisation impact.

Six overarching themes emerged from the qualitative interviews with victims. Two themes represented direct physical and mental impact on victims' wellbeing, these were the *biomedical events* and the *impact on mental health* themes. The other four themes represented the indirect impact and disruption on the victim's self-management plan: *multi-level impact, the impact of complexity, social network involvement,* and *disability discrimination* themes.

GPs input resulted in four overarching themes, which focused on the impact of cyber-victimisation on wellbeing, the impact on mental health, and the use of online health forums. One theme showed the individual variations in GPs responses based on their experiences. The results from the three datasets were summarised and incorporated into one design for the health promotion tool that was shared with the gatekeepers and participants.

Chapter 5

Discussion

5.1 Introduction

This study aimed at scoping and exploring the impact of cyber-victimisation with its various sub-types on the self-management plan for chronic conditions among people living with long-term conditions. In addition, the study findings were then used for health promotion and initiating change, specifically to support victims' wellbeing. A sequential mixed-method design was adopted using a mixed survey, followed by one-to-one in-depth interviews with victims/patients, as well as short written interviews with GPs. A total of 52 gatekeepers helped to recruit participants and 9 gatekeepers assisted in contacting GPs. In total, the study comprised 152 people with chronic conditions who completed the survey, 13 in-depth interviews and 14 interviews with GPs.

This chapter discusses the study findings, relating them to the existing literature and their impact on research and practice. The first section includes a summary of the study and the main findings from each phase. The findings of both the quantitative and qualitative aspects will be presented, then integrated to explore, cross-check and explain their relationship to each other. This will be done concurrently with locating the results within the wider literature. The findings will then be critically evaluated with regard to the theoretical framework underpinning this study. The health promotion element will be further discussed in terms of its improvement and links with relevant literature. The impact of both results, the strengths and limitations of this study will be highlighted. A separate section will be provided to reflect on the research process, what went well

and what could be improved in addition to providing recommendations for practice and future research. The last section of this chapter provides an overall conclusion to this study.

5.2 The diversity of the sample

The majority of the participants in this study were females. Based on the existing literature (Sheridan and Grant, 2007) and this study's methodological approach (Alhaboby et al., 2017a), this could be due to social reasons, because males tend to avoid communicating their stressors in comparison to women. This could have also been influenced by the difference in prevalence of some conditions between genders (Yen et al., 2014). However, the sample had male participants who also experienced cyber-victimisation, of whom one was interviewed. Hence, input from both genders was presented in the survey and interviews. The victimisation and the impact were not statistically different between males and females. In the existing literature, most papers on victimising people with disabilities were male-dominated (Didden et al., 2009; Sofronoff, Dark and Stone, 2011; Yen et al., 2014). When considering victimisation, victim status is more common among females (Sheridan and Grant, 2007), but online victimisation is increasingly affecting males (Fridh et al., 2015). Hence, the relationship between gender and cyber-victimisation is inconsistent in the literature (Didden et al., 2009). This study helped in incorporating input from both genders, in addition to recognising female's attitudes towards participation which could be used to address participation and subsequent support.

The sample included participants from all age groups in both the survey and interviews. This addressed the gap in the literature in which cyber-victimisation has only been investigated among young age groups in nine out of the ten studies included in the systematic review

(Alhaboby et al., 2017b). The only study (Sheridan and Grant, 2007) that included older participants was not focused on people with chronic conditions or disabilities. Hence, the results showed that the risk of online abuse is not restricted to young users and the impact applies to all age groups.

The ethnic background among participants was mainly White, in line with other studies on victimisation (Maple, Short and Brown, 2011). This could reflect the majority of the population in the UK and the higher rate of reporting among the White population (Maple et al., 2012). However, despite this majority, all other ethnic backgrounds were represented in the survey, and two participants from ethnic minorities were interviewed. This ensured representing a potentially oppressed group in this sensitive area.

The participants were exclusively from the UK, mainly from England, but participants from Wales, Ireland and Scotland were also represented and interviewed. The focus of the study addressed a major gap in cyber-victimisation research in the UK, as previous studies focused either on the offline victimisation of people with disabilities (Richardson et al., 2016) or cyber-victimisation among the public (Short et al., 2015b). Hence, no study was exclusively conducted in the UK focusing on people with chronic conditions. This was important to set the baseline to pioneer this issue and build proper support for victims that is context-specific.

The employment status was not statically significant and not represented in the academic literature. Religion was not further examined because some input during the piloting stage considered asking about the religion as offensive (Appendix 19). Occupation sometimes influenced the results, particularly in three interviews where the workplace was included as a source or a scene for the harassment, for example, participant B5. In other cases, this was when the work was predominately online, in the case of participant B12.

The sexual orientation of participants also covered all categories and two homosexual participants were interviewed. Another element of diversity in this study is the disability status, which was found to be both statistically significant and a prominent finding from the qualitative data, hence it will be discussed separately in the following sections.

The inclusivity of the included conditions was affected by the recruitment process due to the denial of access by the gatekeepers of some groups (Appendix 18), hence, it was not a random process and cannot be generalised. Accessibility issues, lack of access and socioeconomic status are also key factors to consider (Sunderland et al., 2014). However, these factors were addressed by the flexibility of research design and by involving people in health promotion.

5.3 The scope of cyber-victimisation

One of the objectives of this study was to explore the scope of cyber-victimisation among people with long-term conditions. It was found that 45.39% of the participants with chronic conditions and disabilities had experienced cyber-victimisation. This indicates that almost one in every two people with chronic conditions is at risk of victimisation. This is especially important when considering the similarity between victims and non-victims in their demographics and conditions. The comparison with the literature is difficult because the prevalence of cyber-victimisation depends on the context and the definition adopted by the researchers (Bocij, Bocij and McFarlane, 2003; Dreßing et al., 2014). Among people with chronic conditions, it was reported to be as high as 41.7% (Fridh et al., 2015), however, this was in a younger age group and outside the UK.

The duration to define cyber-victimisation was inconsistent in the literature, studies considered lifetime prevalence (Mueller-Johnson, Eisner and Obsuth, 2014) or shorter durations

(Wells and Mitchell, 2014; Yen et al., 2014; Gibson-Young et al., 2014). The duration was not statistically significant in relation to the impact of cyber-victimisation. Hence, in this study, the use of criteria to identify cyber-victimisation at any point in life and then compare it with the self-reported victim status was a new approach. However, the self-reported victim status was slightly lower (34.48%) than the prevalence of 45.39%. The cross-tabulation showed it was related to fear. This difference could be due to culture or the underestimation of the situation that emerged in theme 4, hence, this should be further investigated for prevention purposes. In total, 88.24% of the victims experienced fear and distress, and the relationship between fear and cyber-victimisation impact was statistically significant, reflecting how disruptive cyber-victimisation can be (Bury, 1982); this will be discussed further under the theoretical underpinning.

Almost half of the victims considered the victimisation related to their conditions, affirming the role of disability hate in the literature (Emerson and Roulstone, 2014) and in theme 6 on disability discrimination. It could also be indirect due to the longer duration of being online, which is also documented in the literature (Sheridan and Grant, 2007) and emerged as part of communicating online in theme 5.

Most harassers were strangers, unlike offline victimisation (Sheridan, 2005; Quarmby, 2015) and unlike online victimisation of people without chronic conditions (Maple et al., 2012). This implies the need for raising awareness beyond the immediate social network and explains Facebook being the most common platform for harassment. Such a method can also involve the social network of the victims, which emerged in theme 5, which could deplete the victims of social support as discussed in the theoretical framework in section 2.5. However, 13.24% of victims were harassed in online health forums, which was raised as an issue in the social network in theme 5 and by the GPs concerns in theme 4. This could directly impact on the self-management of a chronic condition which increasingly involves online support (Coulson, 2015).

5.4 The diversity of included conditions

The participants reported 340 health conditions and endorsed 999 aspects of the self-management of chronic conditions. The included conditions were categorised under ICD-10 classification and were across different physiological systems (section 4.2.2). This diversity is especially important in this research, first to ensure including individuals at risk, because previous research had predetermined inclusion criteria (Annerbäck, Sahlqvist and Wingren, 2014). Second, this diversity helped to scope the impact on each condition and direct health promotion.

Chronic lower respiratory diseases were highly reported, with asthma being the most frequently reported condition (section 4.2.2). The impact of victimisation on asthma management was studied previously in young patients (Gibson-Young et al., 2014; Annerbäck et al., 2014). However, in this research, despite being the most frequently reported, it was not the condition that affected participants the most. The majority of the participants had more than one condition, and the conditions that were of concern to participants were diabetes, psoriasis, EDS, ME, anxiety and depression.

Diabetes was highly prevalent in the sample, which could reflect its prevalence in the general population (Danaei et al., 2011; Wild et al., 2004; Whiting et al., 2011; Shaw, Sicree and Zimmet, 2010). The qualitative findings confirmed this, as diabetes was common especially across theme 1 on biomedical events and also in theme 5 on the social aspects. Type 1 diabetes type I was more common compared to type 2 diabetes, highlighting an important issue, as the onset of type 1 diabetes occurs at a younger age (Brouwer et al., 2012). Hence, the disruption caused by the diagnosis could not be directly assessed, however, in these participants the disruption shared in theme 3 was frequent. Moreover, studies have examined identity development in relation to type 1 diabetes by considering young participants as emerging adults

(Luyckx et al., 2008; Sparud-Lundin, Öhrn and Danielson, 2010). Thus, the development and management of type I diabetes, in addition to the multi-level impact, could imply a continuous disruptive process (Larsson and Grassman, 2012) rather than overlooking the experiences of people who were diagnosed at a young age (Williams, 2000).

Thyroid diseases were among the conditions that affected the participants and were linked with victimisation from the victim's perspective. The victimisation of people with thyroid diseases has not been studied before and requires further research.

Anxiety, OCD and depression were also included. Among this category of conditions, autism spectrum disorders and Asperger's syndrome were also represented. However, the impact and victimisation of people with these two conditions were less than expected compared to their wide documentation in the literature (Sofronoff et al., 2011)(Kowalski and Fedina, 2011)(Yen et al., 2014). These findings could reflect the inclusivity of the wide range of conditions in this study without predetermined stereotyping. It could also be influenced by the methodology, such as the recruitment process (Alhaboby et al., 2017a) and the inclusion criteria in section 3.3.1.4.

Eczema and psoriasis were reported by 11.76% of participants. Appearance-related victimisation was anticipated in this research because of the documented victimisation of individuals with visible skin conditions (Sentenac et al., 2011a; Sentenac et al., 2011b). In this study, the cyber-victimisation of people with skin conditions was less than expected. Physical appearance emerged from the qualitative data as part of theme 6, but it was focused on impairments rather than skin conditions. Such differences could be explained by the difference between offline and cyber-victimisation as a phenomenon (Sheridan and Grant, 2007). However, it does not eliminate the possibility of victimising people with visible skin conditions online (Mishna, McLuckie and Saini, 2009).

The range of nervous system diseases helped in directing the results in two ways. First, invisible conditions such as MS and ME were highly reported. Their representation could be linked to the identity of participants as discussed before (Alhaboby et al., 2017a). Further, the victimisation of people with invisible disabilities is documented (Quarmby, 2015) and was further confirmed by theme 6 in the qualitative findings. Second, patients with epilepsy demonstrated the severity of the impact of cyber-victimisation on their conditions, in both the survey and qualitative data. People with epilepsy were victimised offline (Hamiwka et al., 2009) or online at a young age (Annerbäck et al., 2014), confirming that conditions documented to be victimised offline, but not studied online or among adults, could be at the same risk of victimisation online. It also reflects how the strict research design can influence results and undermine practice.

Diseases of the musculoskeletal system were reported by 23.68% of the participants, with RA and fibromyalgia being the most common conditions affecting the musculoskeletal system. However, a diverse range of connective tissue disorders was also reported such as hypermobility syndrome, gout and scoliosis. These conditions require further research in relation to cyber-victimisation.

Some conditions such as Crohn's diseases and ulcerative colitis were included. However, due to the high resilience needed for coping with these conditions, it was expected to receive more input from them. The impact here could be underestimated due to the influence of recruitment process because the supportive group specific for these conditions denied the researcher access (Appendix 18). IBS was also expected to be more prevalent due to its connection with stress, however, it was not a common condition affecting the victims in this study. Despite this, the impact on IBS was confirmed during the interviews, while participants with heart conditions reflected the impact of stress more explicitly. Hence, more work is needed to address the impact of cyber-victimisation on these specific conditions.

Ehlers Danlos Syndrome is one of the less common conditions in epidemiology (World Health Organization, 2014). Nonetheless, it comprised a considerable part of the sample as a condition of concern to participants. It was previously reported to be linked to victimisation (Cockroft, 2016). It could also reflect the identity of participants and attitudes towards research because people with less common conditions have started to come forward in research and online communites (Alhaboby et al., 2017a). However, no participant volunteered to be interviewed to confirm this.

The participants were mostly diagnosed by healthcare professionals, as early as birth until the age of 61 years. The disruption to patients' lives was reflected through the fear and distress experienced after their diagnosis in addition to the disruption at multiple levels which emerged in theme 3. Further discussion on this is available in section 5.10.

Most participants had the chronic condition for more than 20 years. This is significant to link with theme 1, where the participants did not acknowledge the impact on their health until a late stage. It also explains the continuous disruption (Larsson and Grassman, 2012) the participants were already experiencing before being cyber-victimised as explained in theme 3.

5.5 The Impact of cyber-victimisation on self-management

Most victims perceived that cyber-victimisation had affected the self-management plan of their chronic conditions. This is a major finding in response to the research question on the impact of cyber-victimisation on managing health, because it precipitates life-threatening conditions (Pinel, 2011). The specific aspects of the impact were addressed based on each element of the self-management of chronic conditions plan and according to each specific condition.

Before victimisation, the most common aspect of self-management involved lifestyle changes such as avoiding triggers, healthy eating, avoiding excessive drinking, and participants' physical activity. After victimisation, the reported impact on self-management was mainly in avoiding triggers, healthy eating, and avoiding exercise. Avoiding particular triggers was reported by patients with diabetes, anxiety, depression, Asperger's syndrome, PTSD, bipolar affective disorder, ME, epilepsy, narcolepsy, RA, restless leg syndrome, fibromyalgia, menstrual disorders, heart disease and EDS. The importance of this lies in the specific aspect of each condition, as lifestyle changes are broad and the trigger is different in each management plan (Newman, Steed and Mulligan, 2004). Additionally, previous research did not specify the changes in the health management plan (Sentenac et al., 2011a; Sentenac et al., 2011b) or did not report them (Fridh et al., 2017). Moreover, the triggers in neurological, mental health, and heart conditions can have a more immediate effect (Pinel, 2011). The implications of this finding are to direct health communication towards raising awareness among people with chronic conditions as primary audience to be aware of the risk of cyber-victimisation and the possible impact of changing their lifestyle-related management on short and long-terms. Theme 1 further explains how these changes in self-management impact on the health condition. It is of note that people with respiratory conditions were anticipated to be affected too (Gibson-Young et al., 2014), but this emerged in qualitative data, theme 1 and biomedical aspects.

Healthy eating was mostly affected among patients with diabetes, depression, epilepsy, narcolepsy, migraine, RA, fibromyalgia, eczema/acne, and menstrual disorders. The role of healthy eating in patients with diabetes and depression is prominent. It could explain the biomedical impact on diabetic patients reported in theme 1, for example, if patients ate sugar-rich food. Regarding depression, one of the major criteria for diagnosis is the effects on appetite (World Health Organization, 1992), hence the impact on eating due to cyber-victimisation is a

disruptive consequence. Healthy eating and avoiding triggers is also an important factor for managing eczema (Bath-Hextall, Delamere and Williams, 2009). Additionally, an impact on mental health exacerbates such conditions (Garg et al., 2001), and this is consistent with the findings on mental health consequences in theme 2.

Exercise was avoided by patients with diabetes, anxiety, narcolepsy, RA, psoriasis, menstrual disorders, and Ehler Danlos syndrome. The role of exercise in managing mental health is recognised (Harris, Cronkite and Moos, 2006). Additionally, the immediate impact could also be seen in patients with musculoskeletal conditions. Hence, it is of concern among patients with psoriatic arthritis or complicated diabetes.

Pharmacological treatment included routine medications by patients and/or prescription medications. After cyber-victimisation, regular medications were mainly affected. Prescription and over the counter medications intake also increased. This could be explained by theme 4, where the priorities of victims changed. It could also be explained by forgetfulness secondary to themes 1 and 2. Theme 6 explains the cases where the medication was sold online by salesmen. The impact on medications was mainly shared by victims with diabetes, depression, PTSD, epilepsy, narcolepsy, restless leg syndrome, RA, menstrual disorders, fibromyalgia, heart disease, and EDS. The importance, in this case, lies in conditions were missing medications can exacerbate the illness, since the adherence to medication is an important part of self-management. However, this aspect of self-management is through enabling people to control their conditions, which was disrupted here. For example, missing medications in epilepsy patients combined with stress resulted in complex convulsions; in heart diseases and diabetes, this can trigger a life-threatening situation (Asche, LaFleur and Conner, 2011). This implies the need for cautious raising awareness to keep the priority with the health condition.

Patients' follow up was mainly with specialists and GPs. However, the impact was on following up with GPs and counsellors. Mental health support was rated first to support offline victims (Galeazzi et al., 2009). Additionally, counsellors played a significant role is supporting cyberstalking victims (al-Khateeb et al., 2017). Consequently, considering theme 2 from the victims which focuses on mental health (section 4.3) and theme 2 from the GPs on psychiatric aspects (section 4.4), missing follow up with mental health support can potentially cause serious complications. Follow up non-adherence was reported by patients with depression, PTSD, bipolar affective disorder, restless leg syndrome, fibromyalgia, menstrual disorders, and heart disease. The importance of this is discussed in support (section 5.6) and GP results (section 5.9).

Monitoring was via self-monitoring, which was affected among patients with diabetes, narcolepsy and fibromyalgia. In such cases, coping with the health condition was disrupted and the reprioritisation issue in theme 3 could explain this. Lab checks were also affected among patients with thyroid diseases, which further emerged from the qualitative data, theme1.

In the survey, there can be social desirability bias due to self-reporting or exaggeration (al-Khateeb et al., 2017). However, this was overcome by designing a mixed-method survey and allowing the victims to provide details of their experiences.

5.5.1 Impact statements

The victims were asked to endorse statements that reflected the impact of cyber-victimisation on their self-management. These endorsements were cross-checked with the impact discussed above in Section (5.5).. The endorsements received were consistent with the cyberstalking victims' responses (Maple, Short and Brown, 2011), but health was added. The results showed that exercise was most affected, in addition to changes to healthy eating and

appetite. Exercise was affected as they were too scared, which could be explained by the concerns for safety in theme 4. It was also affected by being too tired, which could be explained by theme 1, where victims with conditions such as ME had physical upset, or due to the mental health impact and depression in theme 2.

There was also a frequent endorsement of a general feeling of being unwell, despite having the same treatment. Feeling unwell among the victims has been documented in previous studies (Dreßing et al., 2014). This could also be related to physical and mental health in themes 1 and 2. Statements on taking more medications, the impact on monitoring, and follow up also confirmed the previous results. The follow up with GP was mostly affected because of being too scared, which also links to safety in theme 4 and helplessness in theme 2. It is also related to social support in the theoretical framework, which if available, victims might have had more opportunity to adhere to follow up.

5.5.2 The self-management of chronic conditions scale

After documenting the impact through choosing specific aspects of the personalised the self-management of chronic conditions, linking impact with each health condition, and asking the victims to endorse statements that reflect their situations. A further check was made using a validated tool (Ramey, Raynauld and Fries, 1992; Self-Management Resource Center, 2015) to measure the impact of cyber-victimisation on coping. The majority of victims (69.09%) had negative results following cyber-victimisation. It is acknowledged that such results are not perfectly accurate in representing the impact, because the participants already experienced mental distress as will be discussed in theme 2, and it could be influenced by the duration or fear. However, the results reflected the perceived impact on the self-management of the chronic conditions, i.e., the victims' own perception on how this experience affected their coping. Hence,

it could be used as a rough estimate to demonstrate the disruption caused, especially when considering themes 1, 2, and 3.

The difference was positive in only seven cases, i.e., those victims perceived that cyber-victimisation made them stronger. While this is a minority of victims, the strength of their experiences could be further explored to support other victims by identifying attributes (Alhaboby et al., 2017a) or peer support systems (Heisler, 2010; Fisher et al., 2010). The discussion of each theme in relation to these results will further explain the impact.

5.6 Support

A quarter of the victims told their GPs about their cyber-victimisation experience, but their experiences varied and were rated mostly poor or fair. This confirms the role of GP in the literature in supporting victims (Fazio and Galeazzi, 2004). In line with previous studies, the perceived effectiveness of GP support was low (Galeazzi et al., 2009). However, the GPs generally perceived cyber-victimisation as a serious issue (section 4.4). Hence, victims' perceptions could be explained by theme 4, where the complexity and struggle for support had worsened the situation. Taking into consideration GPs input in this study, the line of support could be improved, accompanied by raising awareness.

The informal support received by the victims was also variable from very good to poor. It relatively aligns with previous studies because the support from family and friends was mostly beneficial (Galeazzi et al., 2009), but sometimes the victims were not believed (Sheridan, 2005). Theme 5 could further explain the variations in perceptions around informal support.

Police and victim support were also considered poor, which is consistent with the literature (Galeazzi et al., 2009) (Appendix 24). This could be due to lack of training in the case of the police,

or collaboration between victim support and other support channels. This is further explained in theme 4, because some victims were not aware of victim support or needed action by the police.

5.7 Victims' characteristics

The characteristics of the whole sample and the victims with long-term conditions (section 4.2.6) were similar, the majority of both groups were female, white, with no specific religion. Despite having the same age range, the age of victims was higher in those with disabilities. the victims with disabilities were older. This finding is unlike the literature that focused on cyberbullying among children (Yen et al., 2014; Didden et al., 2009), and cyberstalking of ex-partners (Maple, Short and Brown, 2011). The sexual orientation of the sample and the victims were similar, despite the responses from the victims in theme 6. However, employment status and professionals were less among victims, and less among victims with disabilities. This could be due to the impact of health conditions on physical activity, which may explain why they were online as website admins, online work or for socialising (Sheridan and Grant, 2007). However, this could also reflect marginalisation and stereotyping of disability status (Emerson and Roulstone, 2014).

The comparison between participants with disabilities, and those who were victimised among them was presented in section 4.2.6. Almost all the characteristics were similar, except, slightly more were female and older, will a lower employment rate, particularly as professionals. This resembles the comparison above.

The comparison of the cyber-victimisation experience between victims and the victims with disabilities revealed that more victims with disabilities felt fearful. This could be explained by the role of culture in theme 6, and in marginalising people with disabilities by instrumental support

agencies (Emerson and Roulstone, 2014). They were both victimised mainly on Facebook, mostly by strangers, for a long duration that exceeded a year, and in online health forums. The percentage was slightly higher among victims with disabilities, especially in the perceived relationship between the health condition and victimisation. This could also be explained by theme 6 on disability discrimination and is consistent with previous work in the area of disability hate (Quarmby, 2015), as people with physical impairments and invisible illnesses were both victimised.

Despite the slight differences, the sample, victims, and victims with disabilities had similar characteristics and almost similar experiences, suggesting that alarmingly the risk of being victimised (one in every two people) was the same in all groups. Moderate and extreme fear upon diagnosis were higher in the victims compared to the sample, this will be further discussed in section 5.10.

In section 4.2.6, the conditions that were more than 50% victimised include asthma, COPD, diabetes, thyroid disease, anxiety, depression, mental health illness, MS, ME, epilepsy, migraine headache, RA, fibromyalgia, IBS, heart disease, POTS disease, Raynaud's syndrome, and EDS. In the literature, due to the restricted methodology, these conditions were not studied from the perspective of victimisation before (Alhaboby et al., 2017b) .Some conditions, such as Wilson disease, PTS, bipolar affective disorder, CP, Charcot Marie Tooth, narcolepsy, restless leg, nerve damage, failed back syndrome, chronic tendinitis, wrist dissociation, osteoporosis, spondylitis, chronic coccydynia, intestinal cystitis, gallbladder disease, urinary incontinence, menstrual disorders, cancer, impaired hearing, spinal injury, eye conditions, lower leg amputation were reported by only one participant and this participant was victimised, the numbers were not enough to draw conclusions. However, it is important to highlight them for future research. IBD was not highlighted in Table 26 because less than 50% of people who have IBD and participated were

targeted; among 19 participants, 8 were victimised. However, this does not exclude people with IBD because the main gatekeepers denied access to people living with Chron's disease and ulcerative colitis which could have influenced the results (Appendix 18).

Unlike reported in the literature (Kowalski and Fedina, 2011; Sofronoff, Dark and Stone, 2011), the participant with Asperger's syndrome was not victimised. Nonetheless, this does not indicate that people with Asperger's will not be victimised, because of the diverse spectrum of conditions under the label Asperger's and subsequently having different experiences. People with psoriasis appeared less victimised than anticipated because the literature indicates victimisation in relation to physical appearance (Mishna, McLuckie and Saini, 2009). However, people with invisible illnesses were frequently victimised which highlights other factors as emerged from the interviews and will be discussed under the themes below.

5.8 Discussion on the themes from qualitative data

5.8.1 Discussion on Theme 1- Biomedical Events

The first theme which emerged from the qualitative interviews with the victims was the biological events (section 4.3). It represented the direct impact of cyber-victimisation on the health condition. Hence, it is directly related to the research question on the impact of this experience on the self-management of chronic conditions. The deterioration of health is possibly as a result of disruption to health management. The realisation of the impact was relatively late, which could be due to being more concerned about the cyber-victimisation experience in theme 4, or due to the subjective feeling of distress in theme 2. This could explain the brief sentences to describe health used by the participants because the priority, in this case, has changed, as explained in theme 3. This late realisation could be one of the factors to participate in this study (Alhaboby et

al., 2017b). It also explains the significant relationship between a long duration of more than a year and impact of cyber-victimisation, and identifying self as a victim. The implications of the findings here lie in the importance of raising health awareness, as the victims did not consider the longer term impact on their health conditions until it objectively occurred as complications of the disease or a subjective illness (Boyd, 2000; Alonzo, 2000).

This theme showed an overall deterioration of health, which confirmed the results of the survey, specifically the endorsements in section 4.2.4. When taking into consideration the specific conditions, diabetes mellitus was common across all the categories in this theme. This is in line with the reported impact of diabetes upon victims (Lukaschek et al., 2013), in addition to the high prevalence of diabetes in the UK (Alwan, 2011). The similarity between victims with type 1 and type 2 diabetes was surprising, because the disruption was present in both, despite the documented literature that people with type 1 diabetes have grown up with it as discussed above.

The specific complications were manifested in some patients with COPD, ME, epilepsy, and thyroid disease. Lab findings are objective methods to confirm the deterioration in specific conditions, which was reported by patients with thyroid disease and diabetes. However, these were reported by the victims but not further checked as the phenomenological approach considers patients as experts in their own experiences (Giorgi, 2009), and self-management relies on enabling people to control their own health needs rather than enforcing changes (Greenhalgh, 2009). The specific symptoms resultant from cyber-victimisation are a new addition to the literature (Fridh et al., 2017; Fridh, Lindström and Rosvall, 2015). This confirmed the findings in the survey (section 4.2), and highlighted the importance of health promotion (section 4.5). However, it does not exclude other conditions. Some participants developed migraine headache as a new condition. Primary headaches are themselves a source of traumatic experiences (Lonardi, 2007), which is of concern considering that mental health deterioration in theme 2 is a

potential trigger for worse episodes. Additionally, non-specific symptoms were documented in previous studies (Fridh, Lindström and Rosvall, 2015), and could be further explained by theme 2.

Some participants with diabetes and RA blamed the cyber-victimisation experience for developing these conditions. While this was not clinically assessed, it is of significance to consider patients' perceptions in order to empower them to take control of their health conditions (Greenhalgh, 2009). This signifies the role of health promotion and the GPs in advising patients.

In the theoretical framework underpinning the study, this theme could be located under the disease part, i.e., the objective representation of the health condition following cyber-victimisation, as further discussed in section 5.10.

5.8.2 Discussion on Theme 2- Impact on Mental Health

The second theme represented the impact on mental health and its complications. It was experienced by all victims, through a deterioration of mental health or developing mental health conditions. This affects self-management of health because it requires resilience for coping (Greenhalgh, 2009). The victims reported PTSD, which was documented in the literature (Maple, Short and Brown, 2011), and confirms cyber-victimisation as a traumatic disruptive event. Hence, this theme could be located in the illness part of the theoretical framework i.e., subjective feeling of the victims following cyber-victimisation (Boyd, 2000). Depression and anxiety were commonly of concern, which is consistent with the documented impact of cyber-victimisation on people with disabilities in the systematic review (Alhaboby et al., 2017b). The resultant symptoms and behaviour secondary to distress have a subsequent impact on adherence in self-management, which could further account for the reprioritisation process in theme 3.

The victims went through a stage of helplessness, where cyber-victimisation became an endless experience with survival issues, hence some of them committed or thought about self-harm. These acts could be a direct consequence of mental health deterioration, with the lack of formal support as seen in theme 5, or formal support as seen in theme 4. Self-harm is documented with cyber-victimisation experiences (Yen et al., 2014). Hence, improving support to the victims is recommended. Some participants used this stage to survive, such as attempting to contact human rights organisations. This realisation of rights and the will to fight is a point of strength in which health promotion and victim support could build on to improve other victims' experiences, for example, through peer support (Fisher et al., 2010) as a form of social support. These participants could explain the few positive results in the self-management efficacy scale (section 4.5.2.4.2). Some victims adopted the social model of disability (Bingham et al., 2013), which is also a point of strength to improve involvement in raising awareness, which could be further explained by theme 6. However, this model was contradicted by victims with an invisible illness such as ME. People with ME were fighting the social role and looking for medicalisation. This approach confirmed the stigma associated with invisible illnesses, where the victims entered a process of identity negotiation as presented in the theoretical framework. Hence, they either attempted to hide the impairment, or used physical or online aids, and in both cases, this triggered stigma (Quarmby, 2015; Emerson and Roulstone, 2014) as well as discrimination as will be further discussed under theme 6.

5.8.3 Discussion on Theme 3 - Multi-level Impact

The third theme, the multifaceted disruption, represented the impact of cyber-victimisation through the pre-existing situation and the disruption that followed cyber-victimisation. The first subtheme demonstrated how the management of the chronic condition was relatively fluctuant among most participants, for example, the shock caused by diagnosing the condition. This is in

line with previous studies (Barakat and Wodka, 2006; Lukaschek et al., 2013) and with the biographical disruption model (Bury, 1982) in going through a traumatic experience following diagnosis. However, some participants were relieved by the diagnosis, which was discussed under theme 4. This could be further explained by the disability identity influence on participation as discussed in the methodology paper (Alhaboby et al., 2017a). Young participants also struggled as explained earlier and will be further discussed in theme 5. This overall situation, in turn, provided a 'vulnerable situation' for cyber-victimisation (Emerson and Roulstone, 2014), i.e., the self-management of the long-term condition was not at a stable stage of coping. Hence, it is more in line with a biographical working argument where the trauma is continuous (Larsson and Grassman, 2012). Self-management here is a continuous process rather than a goal to be achieved, and that is why when the reprioritisation occurred in the second subtheme, the progression of the pre-existing complications was faster as seen in theme 1, and health was disrupted (Bury, 1982). This included pre-existing social aspects, such as embarrassment, which could explain the impact in theme 5 and deplete the victims of social support (Gallant, 2003) as will be discussed under the theoretical framework.

The pre-existing situation also lead to having a whole life online and creating online identities. This was discussed under the methodological issues as a finding from this study (Alhaboby et al., 2017a). It could be regarded as a risk factor due to the longer time online (Sheridan and Grant, 2007), but it could also be viewed as a positive point from which to begin with for social support.

When one of the victims used the notion of 'vulnerability' in this theme, it was linked with health and social situation. This perception is in line with the notion of vulnerability in disability studies (Emerson and Roulstone, 2014). This also leads to the connection with theme 5 as a social cognition escalating the vulnerability. Hence, the existing situation was not stable, and

cyber-victimisation was introduced to this situation. This point was found to be a disruptive event in this theme, with disruption to self-management reported in terms of health status, need for recovery, lifestyle and medications. All these are consistent with the findings from the survey (section 4.2).

One of the prominent findings that affected the self-management plan was the reprioritisation process, it could be regarded as a direct impact on adherence. When the victims came under pressure from cyber-victimisation, it became the primary concern. This affected apparently healthy victims in the literature (Dreßing et al., 2014), hence it is alarming if one considers the existing vulnerability discussed above. The disruption here was evidenced as forgetting meals, testing, non-adherence or avoiding exercise. These findings confirm and expand the findings from section 4.2.4. Thus, they necessitate taking action to increase awareness or support, or the direct impact will progress to what was discussed in themes 1 and 2.

There was also an indirect impact on self-management after the disruptive event. Loss of communication, homelessness, changing homes, and unemployment were reported in this study and are consistent with previous studies with adult victims without chronic conditions (Maple et al., 2012; Sheridan and Grant, 2007). Hence, it was not considered in this specific population because this change in social context influences social support (Gallant, 2003), denying the victims access to resources, such as being unemployed, furthermore relying on benefits which leads to further discrimination as will be discussed under theme 6 on disability discrimination. Hence, some victims thought that cyber-victimisation ruined their lives. These perceptions confirmed cyber-victimisation as a disruptive event, and the subtheme of helplessness, which will be further covered in the following theme.

5.8.4 Discussion on Theme 4 - The Impact of Complexity

The fourth theme demonstrated the perceived complexity of cyber-victimisation as documented in the literature (Alhaboby et al., 2016; Short et al., 2014) (Appendix 24). In response to the research question, it was found to be indirectly related to the self-management of chronic conditions by influencing follow up or exacerbating mental health issues discussed in theme 2. This exacerbation came from victim's perceptions that each experience is unique. However, despite variations, the experience was described in patterns, cycles, with various relationships with the harassers. The mention of love perceptions is consistent with cyberstalking research (Short et al., 2014; Sheridan and Grant, 2007), while hate is more consistent with disability hate cases (Richardson et al., 2016). Despite such perceived uniqueness, the victimisation experience had similar aspects to other victims' experiences, hence, increasing awareness among the victims will help in reducing the impact caused by the perceived complexity.

It is also important to note that other diversity elements were perceived as another source of discrimination, such as gender, ethnicity and sexual orientation, further exacerbating the distress in theme 2. However, the cross-tabulation showed no statistical significance (section 4.2.6), thus, using this information for health promotion would be of help to decrease the indirect impact.

Most victims underestimated the situation which was followed by safety concerns. This is consistent with cyber-victimisation cases (Alhaboby et al., 2016; Short et al., 2014). However, the implication of underestimation in this specific population precipitated the impact in theme 1.

Another source of impact on self-management was caused by the support channels, because some supportive channels triggered further distress, exacerbating themes 2 and 3. The

lack of training and support is a consistent issue in the literature (Fazio and Galeazzi, 2004) (Appendix 24). The responses from support channels were not proportional to the impact caused, hence the victims perceived being victimised again by the support, for example police. To resolve this, it was suggested by the interviewee to manage cyber-victimisation as a physical assault. However, a more appropriate approach is training and raising awareness of how to deal with cyber abuse (Fazio and Galeazzi, 2004).

Counselling was perceived differently despite being highly rated as an effective support in the literature (al-Khateeb et al., 2017). This could be either due to subjective differences or the requirement for raising awareness. Victim support was perceived helpful, but not always, and some victims were not aware of this. The role of victim support explains section 4.2.5 in the survey. It is consistent with research (al-Khateeb et al., 2017), but requires further modifications to integrate health support and improve collaboration between different channels.

The experiences with GPs were also subjective. Good experiences were due to being referred to counselling or online support, but counselling itself is controversial in this study (section 4.2.5), despite being helpful to the victims in the literature (al-Khateeb et al., 2017). Online support was also controversial as it could be a source of empowerment, but also a risk (Alhaboby et al., 2016; Alhaboby et al., 2017a), depending on individual experiences. These variations necessitate health promotion, well-trained staff and an integrated approach. Relatively bad experiences with GPs were due to trust issues (Pearson and Raeke, 2000; Cohn, 2015), such as struggle during the diagnostic process, or referring to cyber-victimisation as a non-health issue. Trust was proposed as an integral part of healthcare of quality instead of acceptability (Dyer, Owens and Robinson, 2016). This is consistent with the findings in theme 4, as the partcipants' trust in their physicians had influenced the disclosure of this experience. This could be influenced by under training (Appendix 24), and previous experiences (Galeazzi et al., 2009). Other GPs prescribed

antidepressants in response to theme 2, which is a common approach by GPs. In both cases, this demonstrated a need for training because the source of the problem was not tackled.

Another issue in communicating with GPs is embarrassment, explaining why some participants preferred not to communicate the issue, especially when considering theme 3. However, this precipitated themes 1 and 2, indicating the need for increased awareness, trust and transparency with GPs, which also requires collaboration from GPs.

5.8.5 Discussion on Theme 5 – Social Network Involvement

The involvement of the victim's social network was represented in theme 5, and it is a commonly documented issue in cyber-victimisation cases (Sheridan and Grant, 2007). In this study, it influenced the self-management of chronic conditions in various ways, such as not being believed when talking about cyber-victimisation, or being socially isolated, both of which are common among victims of cyber abuse (Short et al., 2014). The isolation was either as a result of the loss of trust or because the harassers used the victim's relatives and friends to get more information. This has also been documented in cyber abuse cases (al-Khateeb et al., 2017; Alhaboby et al., 2016). The impact of this is the depletion of social support, which was found helpful in cyber-victimisation (Fridh, Lindström and Rosvall, 2015), and it is an important aspect of self-management (Greenhalgh, 2009). The theoretical underpinning of this study considers both the sickness, as a social representation of the condition (Boyd, 2000), and social support (Gallant, 2003). Accordingly, both aspects are influenced by this theme.

Other findings that were common between this study and the literature is when the harassers present themselves as the victims (Sheridan and Blaauw, 2004). Frequent checking of harasser's communication is also common among victims (Maple et al., 2012; Short et al., 2014).

However, in this study, it exacerbated themes 1 and 2, which had potentially led to the overall deterioration of health that was also consistent with the survey findings.

One concern of social network involvement was online communities. The influence of these communities on the recruitment in this study was discussed in the methodology paper (Alhaboby et al., 2017a). However, it goes beyond recruitment to influencing self-management through social support too. Some victims were harassed in online health forums as reported in the survey (section 4.2). Social support was lost when the harassment was online, or online groups were not supportive. It was also apparent when the victims perceived harassment from friends who interfered with their diagnosis and management. Salesman invasion of online support groups was another factor to impact trust and social support. The implication of these findings lies in the need for raising awareness and input from GPs, with trust (Pearson and Raeke, 2000) to have confidence in the diagnosis and self-management plan. When this trust and planning were lost, this led to a harmful struggle as discussed in theme 4, which impacts coping and adherence (Greenhalgh, 2009). This is especially important when considering providing a safer online environment for peer-support to enable people to develop self-management strategies and through this process to become empowered (Coulson, 2015).

The impact of victim's family and friends' involvement was negative despite their supportive roles sometimes. This happened when the harasser targeted them as secondary victims, or when the victims were embarrassed to involve them. In these cases, self-management was affected by the distress in theme 2, leading to the complications in theme 2 and theme 1.

The harasser's involvement was also through claiming to be someone else, such deception is documented against people with disabilities (Alhaboby et al., 2016). Posing as healthcare professionals, such as mental health specialists and GPs, impacted self-management through

follow up and loss of trust, which confirms the results from the survey. Other roles adopted were playing the victim, which is documented in previous studies (Maple, Short and Brown, 2011). This led to confusing the support channels as in theme 4, causing further distress as in theme 2. The harassers used the chronic condition to get closer to the victim, which influences social support as a form of peer support (Revenson et al., 1991).

5.8.6 Discussion on Theme 6 - Disability Discrimination

One of the important findings in this study is the link between cyber-victimisation and disability discrimination. This was reported in the survey and was found to be statistically significant (section 4.2.6). It also emerged as a recurrent theme from the accounts of victims with self-reported disabilities. Considering that disabilities and long-term conditions hugely overlap (Equality Act 2010), there are differences between self-reported disability and the definition in law (Equality Act 2010). However, this study relied on self-reported disability due to the phenomenological philosophical stance (Giorgi, 2009) to reveal the experiences of people with disabling conditions, in addition to people with invisible illnesses (Alhaboby et al., 2017a). Including disability as part of the personal identity, as discussed above, helped to identify positive points to start with for health promotion and contacting gatekeepers.

Disability hate incidents are well documented (Emerson and Roulstone, 2014; Burch, 2018), with an argument over adopting the social model of disability (Bingham et al., 2013). The targeting of people with disabilities is also documented in cyberbullying cases of young victims (Didden et al., 2009). Hence, this study confirmed these findings and extended them to reflect the impact on adults with disabilities, and the link to the health condition.

The cases of invisible disabilities were complicated by targeting the victims because of not looking ill. To overcome this, the victims with multiple conditions used the most physically apparent impairment to legitimise the health condition as a sickness (Boyd, 2000). This was one of the factors to participate (Alhaboby et al., 2017a). Some victims created online persona, which leads again to themes 5 and online risks. The case of legitimising the health condition puts this theme at the side of 'sickness' in the theoretical framework as will be discussed in section 5.10.

Normal life could be described as living independently, which includes the use of the Internet, hence involves risk taking (Seale and Chadwick, 2017). The perceptions of Internet risks were documented to include the engagement with bullying, negative online contact, or exposure to harmful content (Seale and Chadwick, 2017). This is consistent with theme 6, on inclusion people with disabilities, in addition to the controversial risk of online social support as an element of self-management. The harassers used the health condition to get closer to the victims in theme 5, while in this theme, the medical information on the health condition was collected to accuse victims of fraud and cut their benefits. Accusations of fraud are common against people with disabilities (Emerson and Roulstone, 2014) and they are fed by media representation and politics (Briant, Watson and Philo, 2013; Burch, 2018). It also included calling the hotline and offending victims, raising a concern about the importance of the training of support channels to identify cases of cyber-victimisation. This is important because cutting the benefits created distress as in theme 2 and unstable circumstances presented in theme 3. Accordingly, the victims perceived exclusion, which could be linked to the deprivation of social support that exacerbates further complications (Revenson et al., 1991). Accordingly, the presence of disabled victims and offenders in this theme confirms the role of distress caused by cutting their disability benefits, and the attempts of online peer support among the disabled community online, which is a positive point to start with for improving support.

5.9 Discussion of GP results

The GPs were diverse in terms of gender, ethnicity and clinical experience. By employing the same codebook, the themes from GPs input were relevant to the themes from the victims.

The first theme was the impact of cyber-victimisation on the health condition. GPs confirmed the impact on wellbeing, chronic conditions, and self-management. However, only one GP mentioned the social aspect (section 4.4). This could be regarded as a positive considering that doctors historically tend to adopt the biomedical model (Marinker, 1975). It could also reflect a disadvantage if theme 3 from the victims was considered, where the legitimisation of the impact on health caused a struggle (Boyd, 2000). This could be further explained by GPs' theme 3, which demonstrated subjective differences between the GPs. GPs who encountered victims of cyber abuse were more understanding. Nonetheless, the advice was still within the remit of referrals, mental health support and considering it a criminal issue for the police to address. GPs who did not encounter such victims underestimated the situation. These subjective differences have been documented in previous studies (Kamphuis et al., 2005), and switching the source of online abuse is a common response from under-trained support (al-Khateeb et al., 2017). The implications of this are mainly for health promotion and practice. There is a need for the victims to understand the GPs' stance and their medical input on the impact of chronic conditions. This was used for health promotion (section 4.5) to encourage the victims to communicate health issues and improve trust in doctors (Pearson and Raeke, 2000). However, this needs further work to support the GPs, in terms of time, resources and training to provide the proper support. This was acknowledged by only one GP, and was undermined by the individual variations between GPs (section 4.4).

The second theme from the GPs was on the impact on mental health. Their clinical experience brought non-specific stress symptoms which could be explained by the victims' theme 2 and survey (section 4.2). The specific clinical concerns were anxiety, depression, panic attacks and phobia, which are consistent with the literature (Fridh, Lindström and Rosvall, 2015), as well as the findings from the survey and theme 2. However, in the qualitative theme 3 and in the survey, this recognition of mental health alone was not enough because it was tackled mainly by medications rather than tackling the source, which takes the situation back to the impact of complexity and the need for training.

Another theme was the impact on the use of online health forums. The participating GPs acknowledged their referrals to online health support. This is convenient considering the limited time GPs have in the UK (Royal College of General Practitioners, 2013), but important when considering that some victims were targeted in online health forums in the survey (section 4.2.3), and in theme 5. Hence, some victims blamed their GPs for being victimised (section 4.3). To mitigate this, some GPs were aware of online risks in these forums, online behaviours, and they warned their patients about the accuracy of information and salesmen. Hence, this is a point of strength to use to promote a safer online health environment as a new approach for self-management (Pereira et al., 2015), which is of help to the patients who are mostly online as documented before (Sheridan and Grant, 2007) and in theme 5.

5.10 The results and the theory

5.10.1 The results in relation to theories in the literature

In studies focusing on the cyber-victimisation of people with chronic conditions, different theories were adopted (Fridh, Lindström and Rosvall, 2015; Alonso, 2004). However, none of them were applied to the impact compared to this study.

The most relevant theoretical approach to this study looked at the Model of Social Support (Fridh, Lindström and Rosvall, 2015). It was explained by two approaches: the main effect model which implies that social support is always helpful; and the stress-buffering model which states that supports is relationally based on the trigger (Fridh, Lindström and Rosvall, 2015). This argument supports the findings of this study and fits within the theoretical framework from the sickness and identity aspects. Thus, awareness raising in health promotion could influence how the targeted individuals would share their experiences with their social networks (section 4.5).

With regards to the role of disability in relation to theory, both the biomedical and social models of disability (Alonso, 2004; Bingham et al., 2013) emerged from the data. In theme 6, there were subjective differences between people with the disabling condition. The most common approach was adopting the social model, as seen in themes 2 and 6, which indicates the role of social support. However, the biomedical model was important for people with invisible illnesses, such as ME. This supports the suggestion to adopt both models to ensure providing the appropriate support to cover medical and social factors.

There were other less relevant theories in literature. Yen et al. (2014) discussed the reinforcement sensitivity theory, anxiety was addressed in response to expected punishment, reward as enjoying the situation, both of which focused on the offenders rather than the victims.

The impact on self-esteem was tackled which could be lightly connected with theme 3 as a complicated situation. The Theory of Mind was employed to explain victimisation by blaming the deficit in social skills among the patients (Kowalski and Fedina, 2011). This is more of a victim blaming approach that facilitated both themes 3 and 6. The Theory of Mind was also adopted using the 'vulnerability' discourse, in which gullibility which was vulnerability to be tricked, and credulity was the tendency to believe something (Sofronoff, Dark and Stone, 2011). Both constructs also enforce victim blaming, undermine the biopsychosocial aspect, and facilitate theme 4 on social network involvement and isolation.

Accordingly, the findings in this study confirmed the disruption caused by the interaction of both the chronic condition and cyber-victimisation, and self-management is rooted in the biographical disruption (Morden, Jinks and Ong, 2015).

5.10.2 The results from the lens of the theoretical framework

The findings in this study suggest that the impact of cyber-victimisation on people with chronic conditions fits within the theoretical underpinning discussed in section 2.5. Each theme from the qualitative data was discussed in relation to the survey findings and within the theoretical framework of this study as summarised in Figure 20 and further detailed below.

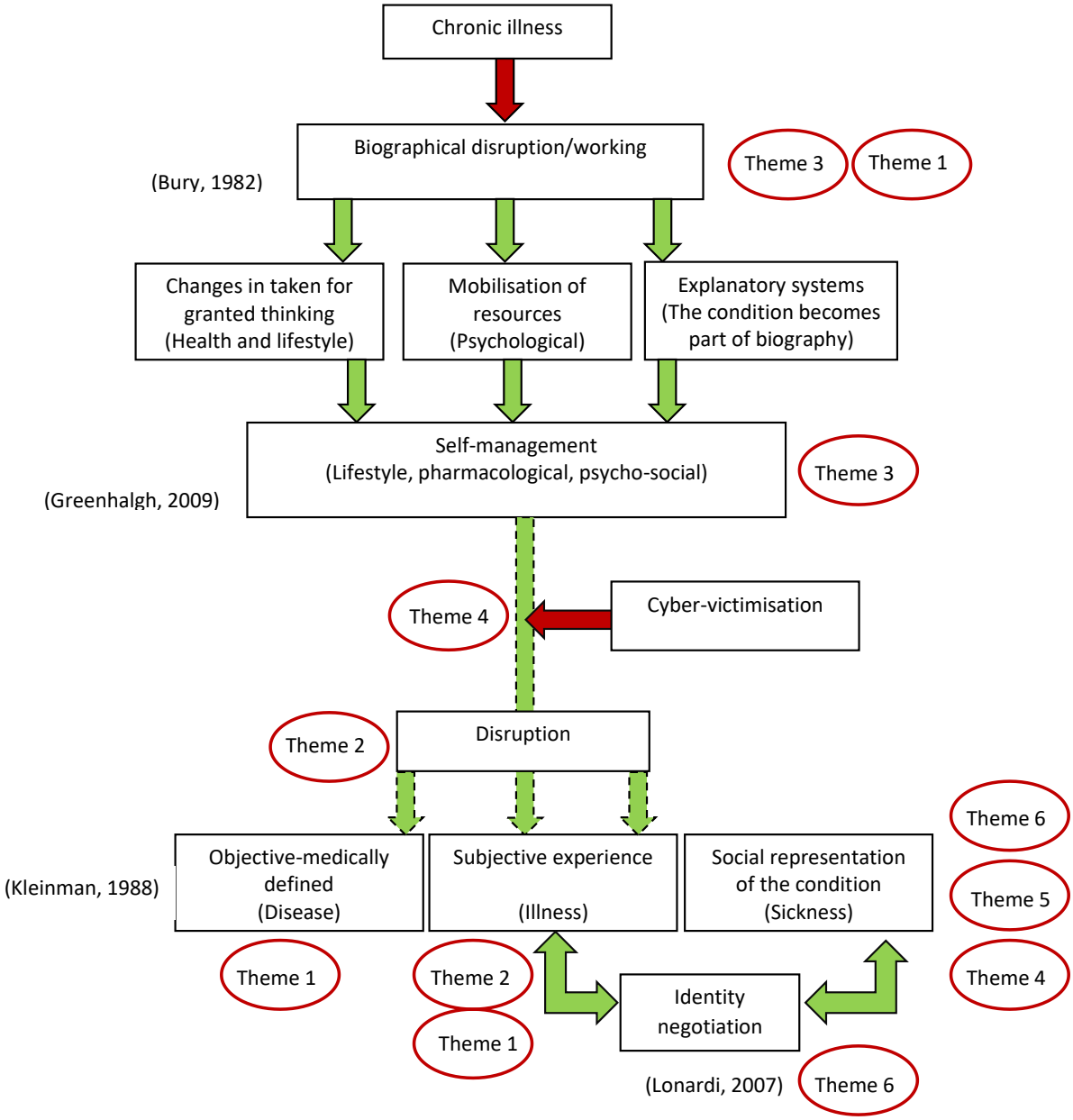

Figure 20. *The relationship between the theoretical underpinning and the qualitative results in this study*

The diagnosis of a chronic condition brought fear and distress to the participants as reported in the survey (section 4.2.2). This reaction is consistent with the concept of biographical disruption model, which considers the diagnosis of a chronic condition a disruptive event that changes life (Bury, 1982). However, young participants did not remember the first reaction to their diagnoses, yet they did not reach a point of self-management stability, for example, they struggled with follow up and social interactions in themes 3 and 5. Hence, this explains the existing vulnerability and multi-level impact, because self-management presented as a continuous process in theme 3. This is more consistent with the term biographical working (Larsson and Grassman, 2012), which considers the diagnosis of chronic condition as a disruptive event, but it also requires continuous working to deal with the disease progression and complications. Thus, the biomedical complications experienced in theme 1 are also located in the upper part of the framework, as the progression to complications and developing new conditions resulted in further biographical working (Larsson and Grassman, 2012).

After the diagnosis of the chronic condition, the explanatory systems, mobilisation of resources and the thinking system were affected. However, as explained above and in theme 3, this was not an isolated incident (Williams, 2000), but rather a continuous process (Larsson and Grassman, 2012). Therefore, the healthcare professionals' role in facilitating self-management is necessary because of its dynamic nature (Schulman-Green et al., 2012). However, changes towards considering the social aspect of health is academic rather than clinical (Alonso, 2004), it improves the doctor-patient relationship, but clinicians are generally reluctant to implement it (Alonso, 2004). This could explain the subjective variations and the negative instance among the GPs, which in turn, influenced victims reporting in the survey and in their experiences in theme 4.

At this 'existing vulnerability' stage, cyber-victimisation was introduced to patients' lives. The complicated situation and perceived uniqueness of each individual case, as presented in theme

3, labelled cyber-victimisation as a disruptive event in victims' lives. This appeared in the distress and fear reported in the survey (section 4.2.3), as well as in mental health complications in theme 2. It is of note that the reference to vulnerability varied between healthcare professionals who adopted the biomedical model (section 2.5.3) and among the participants themselves because most of victims adopted the social model, which will be further discussed below.

Cyber-victimisation as a disruptive event resulted in biomedical changes, such as physical complications and new health conditions, which influenced the biomedical section in the framework, known as the disease (Boyd, 2000). The subjective experience, the illness, was also disrupted. Most participants experienced mental health complications reported both in the survey section and in theme 2. Hence, the subjective illness was disturbed due to both physical and mental complaints. Biomedical and mental health complications were also endorsed by the GPs (section 4.4). This was a point of strength to start health promotion (section 4.5). The third aspect affected was the sickness, which is the social representation of the disease (Boyd, 2000). Theme 4 is located in this part because of the victims' struggle to find the appropriate support. The victims attempted to get support from the police, healthcare professionals and victims support. Each of those channels required legitimisation of the impact of cyber-victimisation as a social representation. This is consistent with the literature, because people tend to judge the condition, caring more about the sickness as a social issue (Boyd, 2000). In this case, it affected the participants because the underestimation and lack of training affected the legitimisation. Hence, raising awareness is essential and trust issues with their social network. This leads to deprivation of social support or troubled social interference (Revenson et al., 1991). This is of concern, because social support is generally positive in self-management discussions, especially diabetes, asthma, heart disease and epilepsy (Gallant, 2003). This highlights the important role to mitigate the impact in theme 1, where these conditions were complicated. However, problematic social

interactions in troubled attempts to help aggravate mental health (Revenson et al., 1991), which potentially exacerbates theme 2. Hence, less support as seen in theme 5, or problematic support both lead to negative consequences (Revenson et al., 1991).

Theme 6 on disability discrimination was applicable to both the social/sickness and identity negotiation parts of the theoretical framework underpinning this study (section xx). Disability status and claiming benefits required medical legitimisation, which affected the social representation of the sickness (Boyd, 2000). The case was different between visible and invisible conditions, this allowed a cycle of identity negotiation on whether to disclose the illness to the wider social nework (Green, Todd and Pevalin, 2007). This cycle included disclosing the condition as a sickness, or keep to self as an illness. Identity negotiation was used to create online identities and incorporate the disability as part of the identity (Alhaboby et al., 2017a). It is suggested that the meaning behind the diagnosis of having an impairment is also disruptive (Morden, Jinks and Ong, 2015), hence, having a disability could be disruptive, which aligns with the previously discussed argument on the role of social identity in encouraging disabled people to confront discrmination (Alhaboby et al., 2017a).

5.11 Validity and reliability

Validity is a concept in research that indicates accuracy, it is the degree of approximation between what was intended to be examined and reality (Guest, MacQueen and Namey, 2012b). Specific types include face validity, which is the degree to which an indicator makes sense, and external validity, which indicates the generalisation of results (Guest, MacQueen and Namey, 2012b). Further, reliability is the consistency or reproducibility of a measurement (Black and Champion, 1976). Due to the flexible nature of qualitative research, these terms are not applicable as the present research was a mainly qualitative mixed-method study (section 3.2). Validity in

qualitative research is described as trustworthiness, credibility or conformability, which could be described as the confidence in the findings (Lincoln and Guba, 1986)while the dependability of findings is used instead of reliability (Guest, MacQueen and Namey, 2012b). In qualitative research, the transparency of methods feeds into the face and external validity, while due to the flexibility in data collection, reliability is less important (Guest, MacQueen and Namey, 2012b). The transparency in writing the methodology and results allows the reader to judge the research findings, but this is not always guaranteed (Guest, MacQueen and Namey, 2012b). However, there are several indicators that were adopted to ensure the credibility of this study.

The credibility at the research design stage could be ascertained by triangulation and team-based instrument development (Sharts-Hopko, 2002). This was addressed through cross-checking the results using different data sources, in addition to piloting the instruments to get input from experts in the field (Appendices 15,17,19). At the data collection stage, credibility is addressed through adjusting the structure of instruments to fit the purpose (Krueger and Casey, 2009). Adjusting was addressed at the piloting stage of instruments (Appendices 11, 13 & 15). The flexibility of qualitative methods could undermine the credibility here (Guest, MacQueen and Namey, 2012b). However, the feedback from the participants and gatekeepers (section 6.3.2), changing the recruitment strategy to adopt the partcipants' needs and snowballing (section 3.3.4) supported the credibility of this work. At the data analysis stage, the transcription verbatim and consistency support the trustworthiness of the findings (Guest, MacQueen and Namey, 2012b). In this study, the interviews were transcribed by verbatim during the same week as the interview. There was no translation because the study was UK-based. The interviews were consistent in terms of the identity of the interviewer and using the same tools. The transcription was also supported by building a precise codebook (Appendix 21), and adopting the same codes for the GPs to support triangulation of results. Triangulating data sources confirms trustworthiness,

especially if this showed convergent results (Guest, MacQueen and Namey, 2012b), which is the case here due to the similar findings in the three datasets. The findings from the quantitative data and qualitative data were convergent (section 5.8), and the themes from the victims and GPs were relatively similar (section 5.9).

Another way to assess the credibility at the data analysis stage is providing an audit trial (Sharts-Hopko, 2002). This was provided through the documentation of analysis steps, codebook revisions plus internal reviews during team meetings. Additionally, negative case analysis mitigates analyst bias (Mays and Pope, 2000). In the qualitative results, negative instances were carefully considered, and they were presented in all relevant themes and GP results. Lastly, supporting themes with quotes (Chenail, 1995) enhances the credibility of results. Quotes were provided to support each theme and allow the reader to assess the results (section 4.3 & 4.4).

There are also several quality criteria of good inclusive research in disability studies. These include being authentic, which means being recognised by people involved (Seale et al., 2014). In the area of health research, there are six concepts of validity according to the International Collaboration for Participatory Health Research (Seale, Nind and Parsons, 2014; International Collaboration for Participatory Health Research, 2013). Firstly, the participatory validity, it implies the engagement of stakeholders in the research process. This was addressed in the recruitment process (Alhaboby et al., 2017a), and in involving both the participants and gatekeepers in health promotion (section 4.5). Secondly, inter-subjective validity, which indicates the research being meaningful. Thirdly, contextual validity reflects the research importance to the local context (International Collaboration for Participatory Health Research, 2013). Both the inter-subjective and contextual validity were addressed in this study, because the victims were isolated and marginalised as discussed in theme 5, and this issue was found to be prevalent in the UK (section 2.3), while the research in this area in the UK is limited (Alhaboby et al., 2017b). Fourthly, catalytic

validity indicates presenting new possibilities for social action. Fifthly, ethical validity, which implies providing sound and just outcomes (International Collaboration for Participatory Health Research, 2013). These two concepts of validity were addressed through tackling an important issue and initiating change using the results of this study through raising awareness (section 4.5). Sixthly, empathic validity is by increasing empathy among participants (International Collaboration for Participatory Health Research, 2013), this was addressed through the recruitment process and identifying the influence of the disability identity and victim status in supportive groups (Alhaboby et al., 2017a). It was also addressed through raising awareness and providing theme-based stories to show the victims that similar people had gone through similar experiences.

5.12 Summary

This chapter discussed the results of this study in relation to each other and to the existing literature. Triangulating the results from the different datasets showed that the findings are convergent. The results from the survey were further interrogated in in-depth interviews with the victim, then informed by the input from the GPs. Most of the results are consistent with the existing literature and filling the gaps identified at the literature review stage. The validity of the results were discussed from a general perspective and in relation to the quality criteria for the research with people having disabilities, which highlighted the strengths of this study.

Chapter 6

Conclusion

6.1 Introduction

This chapter summarises the overall input of each stage in this study to the existing literature and practice. This will be through identifying the impact of the findings, the strengths of this work and its dissemination. The chapter provides an overall conclusion, followed by a section illustrating the researcher's reflection on this research journey.

6.2 The impact of this study

In addition to the significance of each element of this work as discussed in Chapter 5. The strength of this study is the insight into the rapidly growing virtual reality of a group at risk, thus, this study pioneered a new area of research and bridged some of the gaps in knowledge and methodology identified in the literature. The context of the study in the UK is another strength, due to the increasing issue of cyber-victimisation (Maple et al., 2012) and the limited studies compared to the international context (Fridh et al., 2017). Additionally, the study confirmed that cyber-victimisation is a public health issue (Annerbäck et al., 2014), but also took action, initiating health promotion through raising awareness (Appendices 26-30).

This study contributed to empowering the victims with long-term conditions. This was through bridging the gap through the qualitative aspect, from the 'victim's' perspective by adopting a phenomenological approach and considering the participants as experts in their own experiences (Giorgi, 2009). In a critical review (Seale and Chadwick, 2017) of 'normal' life for

people with intellectual disabilities and Internet use, it was concluded that research requires more in-depth input and risk taking in design, implementation and analysis (Seale and Chadwick, 2017). Thus, in-depth interviews with the victims represented a necessary aspect, especially due to the lack of qualitative elements in previous research (Mishna, McLuckie and Saini, 2009) , the social isolation (section 2.5) and difficulty experienced by the victims in getting an appropriate formal support (section 4.3.5) (Appendix 24).

Another impact is through highlighting the diversity of the victims which could guide future work. For example, the strengths of the survey include the diversity of the sample, in terms of ethnographic diversity (section 4.2.1), and the variety of included conditions (section 4.2.2). This helped in the scoping of the phenomenon of cyber-victimisation and the direction of future research towards highlighted conditions as discussed above. Another addition was using two ways to identify the victims, by providing a question with the criteria of cyber-victimisation or self-reported victim status, as discussed in section 2.3.2. Previous studies either adopted self-reported victim status or only provided the criteria (Sheridan and Grant, 2007; Maple, Short and Brown, 2011). Investigating fear as an influencer on the impact of the cyber-victimisation is another aspect that was statistically significant. Moreover, exploring the duration of victimisation because it is variable in the literature (Dreßing et al., 2014; Maple et al., 2012; al-Khateeb et al., 2017). Additionally, despite adopting a phenomenological approach, a validated tool was used to assess the impact of cyber-victimisation on the self-management of chronic conditions (section 2.2.2). Due to the subjectivity of the responses to this tool, the results were cross-checked with other questions in the survey on specific aspects of self-management, and with the themes from the victims, all of which demonstrated a negative impact on health. This was strengthened by the significant relation between long duration and cyber-victimisation impact, which was further explained in the physical consequences in theme 1. Hence, it confirmed a link between health,

disability and victimisation. Disability is increasingly being studied from public health perspective (Möller, 2015), and health promotion is an approach linking disability and public health, through equality and improving wellbeing. Thus, the impact on the health condition on longer term brought the literature from different disciplines together such victimisation, public health, and disability studies.

This engagement with the gatekeepers helped in reaching the participants directly, establishing access to closed communities which have an important role in supporting the victims. The participatory process is an important strength, which was through the recruitment process and in involving the victims and the gatekeepers in the development and dissemination of the health promotion (section 6.3.2). This allowed an initial step for participatory research to be further implemented in the future as participation bridges the gap between theory and practice (Jackson, 2014). It also encouraged future work and collaboration with other supportive channels, such as the police and law firms, which is required to provide appropriate support (Appendix 24). Hence, this study had an impact in directing support channels and informing policy by uncovering the extent of cyber-victimisation among people with long-term conditions.

6.2.1 The impact of the systematic review

Following the publishing of the systematic review (Alhaboby et al., 2017b), one of the gatekeepers invited the researcher to communicate with an online support group for people with chronic conditions. This invitation was because of the relevance of this work to them and the necessity of raising awareness.

From research perspective, the systematic review identified gaps identified in the research, which may necessitate the need to broaden the scope by addressing more conditions and

acknowledging differences between heterogeneous health conditions in terms of consequences. This study took this recommendation forward by highlighting more specific conditions to cover in the findings and the discussion. Other recommendations include allowing flexibility and accountability to patients/victims in research design, education on victimisation and health consequences, and improving primary care. These aspects were also covered in this study by employing qualitative methods and involving the GPs. Further implications of the systematic review are summarised in Table 40.

Table 40. *The implications of the systematic review on research, practice and policy in relation to cyber-victimisation and chronic conditions (Alhaboby et al., 2017b)*

<table>
<tr><th>Critical issue identified in this systematic review</th><th>Implications on research</th><th>Implications on practice</th><th>Implications on policy</th></tr>
<tr><td>Most data was collected via adopting a cross-sectional design, with a pre-determined set of questions, and influenced by disciplinary variations.</td><td>Need for flexibility in research design and accountability to victims to understand their lived-experiences to inform interventions.</td><td rowspan="2">• Consciousness in evaluating cyber abuse cases.
• The evaluation of cases should consider that cyber abuse is not restricted to documented conditions, or documented populations (young age, males or people from White ethnic backgrounds).</td><td rowspan="3">• Interdisciplinary collaboration to inform policies on cyber-victimisation of people with chronic conditions.
• Considering the interconnections between diversity elements and cyber abuse in policies.
• Research-informed demarcations of cyber offences to facilitate health and legal remedies.
• Dealing with people with chronic conditions as a group at risk requiring</td></tr>
<tr><td>Reported outcomes were influenced by the diversity of samples (age, gender, ethnicity)</td><td>Inclusivity in future research to cover older age groups, female gender and ethnic minorities.</td></tr>
<tr><td>Inconsistency in identifying cyber-victimisation cases (frequency of incidents, duration, and terminology).</td><td>Working towards common criteria and terminology to identify cyber abuse cases to improve international and multi-disciplinary communication, and</td><td>Terminology used by researchers and victims should be further interrogated during consultations to understand the case before making a final judgment.</td></tr>
</table>

	subsequently provide proper support to victims.		protection from cyber offenders. • Improving primary health care as one of the supportive channels to counteract cyber abuse of chronically ill patients. • Awareness raising (professionals and the public), education, and training on cyber abuse risk and impact upon victims.
Differences in identifying chronic conditions with a tendency towards using general and broad terms while referring to a heterogeneous group of conditions.	• Broaden the scope of research to investigate specific health conditions. • More specific criteria in identifying health conditions.	Collaboration between researchers and healthcare practitioners to identify patients/victims and increase resilience in diverse populations.	
Cyber-victimisation is prevalent among people with long-term conditions, with consistent higher risk of being targeted across studies.	• Looking for specific estimates of cyber abuse in response to specific conditions. • Researching the impact of cyber abuse on the self-management of chronic condition and prognosis.	• Considering the risk of cyber abuse when following up with patients and when referring them to online health forums. • Recognising the impact of mental health consequences on health self-management of each specific condition. • Consider cyber abuse as one of the underlying causes of non-specific somatic health complaints presenting to primary care.	
Cyber abuse has mental health impact on victims (depression, anxiety, distress, PTSD and self-harm)			
Somatic health complaints as nonspecific symptoms presenting to primary care.			

6.2.3 The impact of identifying methodological challenges

Following the publishing of the methodological part of this study (Alhaboby et al., 2017a), the researcher was contacted to give research advice to new researchers in the field. Moreover, the recruitment process was challenging, but it could be regarded as an integral aspect of this

study. These challenges were published in a peer reviewed journal (Alhaboby et al., 2017a). It helped in recognising the characteristics of online self-representation of people with disabilities more specifically, accompanied by highlighting positive aspect of online identity to provide tailored research methods or interventions. For instance, positive aspects identified included viewing self with the status of being a disabled, victim, or having invisible illnesses in internet communities, and online inclusivity. These could be potential points to consider during early stages in future research with people having long-term conditions.

6.3 Dissemination

This section discusses the dissemination of the work conducted in this study and its implications on the existing situation in the UK in relation to cyber-victimisation and long-term conditions.

6.3.3. Peer reviewed papers

The outputs of this work were listed in the beginning of the thesis and Appendix 4. This is an important aspect in dissemination because it helped in reaching the research community in the UK and cross-border. This triggered further work and helped in establishing collaborations (Appendix 4)

The papers helped in backing up the activists in the field by providing academic evidence to support the victims who were isolated and confused. This academic support can potentially change the current marginalising situation as discussed in section 3.6.

6.3.1 Evidence to the House of Commons

The most recent issue in the UK legislation related to this work is a petition raised to criminalise cyber-abuse of people with disabilities (Parliament, 2018). Subsequently, an inquiry in January 2018 was launched by the House of Commons, and I received an invitation as an expert in the field to provide written evidence on the impact of cyber-victimisation of people with long-term conditions. I supported the inquiry with input from this study (Alhaboby, 2018b) and it was well-received to be used by the Committee to revisit the legislations on online abuse of people with long-term conditions. This was an important step to make the voices in this research heard, change the situation and prevent the struggle for support.

6.3.2 Disseminating health promotion design

The dissemination of health promotion tools is necessary to assess the achievement of the aims and to address the impact and failures (Cragg, Davies and Macdowall, 2013), which in turn lead to action and improving the outcomes. It is thus better to involve all participants in this approach, which also enhances the validity of the results (section 5.11). Formative, process, impact and outcome evaluations can be used to assess health promotion tools. Formative assessment is performed through piloting (Cragg, Davies and Macdowall, 2013). This method was adopted here to allow a participatory approach. Process evaluation was adopted to reflect on the recruitment process (section 3.6). Lastly, impact and outcome evaluations (Cragg, Davies and Macdowall, 2013), establishing whether the tool has achieved its aims, is an approach that was integrated with the formative approach through the questions on usability to the gatekeepers (Appendix 26). However, impact and outcome evaluations are not entirely applicable at this stage due to the relatively recent acknowledgement of this issue, social isolation experienced, and the complex multi-level impact of cyber-victimisation that requires long-term work at individual,

community and policy levels. However, the initial impact could be demonstrated in the interest of support groups to sponsor the health promotion design, and inform legislation in the UK.

One of the challenges facing health promotion is its domination by the biomedical model and political context (Jackson, 2014). This was overcome by the flexibility of this study and the philosophical stance which allowed the researcher to integrate participants' voices and change the researcher's position towards the social model as discussed in the researcher's reflection (section 6.5). As a consequence, both participation and online support groups carry the potential for better communication with people who go through this experience for support, and with policy makers to advocate for change.

Participatory input in health promotion allows the target audience, the people with disabilities or professionals, to state their preferences (Neuhauser et al., 2009). Participatory action research was adopted to get input on people's needs from their own perspective for health promotion purposes (Ekberg et al., 2013). Thus, a participatory approach is a potential approach to communicate with vulnerable groups about health and wellbeing (Neuhauser et al., 2009). This supports this study's approach to involve both the participants and the support groups to provide their input and improve the design based on their own needs and future use, therefore, it was adopted in dissemination of this study.

In participatory research, the participants are engaged in the research process as active co-researchers (Seale et al., 2015). However, in such an approach, participation has a range, which could be minimal or in all of the research stages (Jackson, 2014). For example, full participation could be challenging and not always applicable, as in research with students (Seale, Nind and Simmons, 2014). Therefore, in this study, there was an intention to involve the participants as co-researchers, but this was limited by the unknown scope of the issue

(Alhaboby et al., 2017b). The scope of the issue was one of the study aims, hence the full employment of participatory methods was not applicable. However, this could be an initial step in raising awareness and could be further implemented in future research. For example, considering theme 6 on disability discrimination, the statistical significance between disability and cyber-victimisation, and how the disability identity had influenced attitudes towards participation (Alhaboby et al., 2017a), these points could be adopted to plan future participatory research with more input from the participants.

6.3.2.1 The response from the participants and gatekeepers

The input from gatekeepers and participants in response to receiving a draft of the preliminary design for the promotion tool (Appendices 27-28) was collected and thematically analysed (Braun and Clarke, 2006). A total of 12 responses were received, 8 from supporters and 3 from participants, and one response was from both a supporter/participant. It is of note that the supporters were either working to support the victims or to support people with long-term conditions. The presentation of the emerging themes was based on comparing two main areas, what was good for health promotion, and what could be improved (Guest, MacQueen and Namey, 2012a), as summarised in Table 41. The approach of comparing themes in response to these two main areas was helpful to identify points for improvement (Guest, MacQueen and Namey, 2012a). A total of eight gatekeepers provided their details to be added to the design to encourage the victims to contact them and get support, these were:

- Diabetes UK
- Revenge Porn helpline
- Open Forest Health blog
- Cybercare
- MIND
- MIND BLMK
- National Stalking Helpline

- Network for Surviving Stalking

In addition, two journalists working at the Guardian and active in disability hate cases offered disseminating the health promotion part.

6.3.2.2 Theme group A: What went well?

In response to the good aspects of the health promotion design, four main themes emerged: approachable presentation, active participants' voice, highlighting an important issue, and encouraging future work. The explanation of these themes is below and Table 41 illustrates examples from each theme for comparison purposes.

The **approachable presentation** was endorsed in most of the responses. The respondents thought the design was presented in a new style that is informative, clear and easy. The visual presentation was described as pleasant and eye-catching. The use of bullet points was considered positively. One respondent described the poster as easy.

The presence of the **participants' voice** in the design was considered a positive aspect that reflected the victim's experience and brings real stories. It was thought that having real stories and direct quotations had a bigger impact on raising awareness than sharing a report of the results. This was also confirmed by victim support workers.

The respondents also considered the tool **tackling an important issue** and bringing it to people's attention. The respondents were pleased to find an awareness tool that highlights a serious, common and worrying issue. Some of them considered it an excellent initiative.

Some respondents considered the tool **influential** in different aspects. One aspect was research, because the tool helped researchers in the area to think about what to do, how to

communicate with participants, how to present themes, and also proposed discussing methodology challenges to gain input from this study. Another influence is thinking about the importance of this tool that should be followed by commitments to legal remedies. One respondent shared the idea of adopting the same approach in other work to develop different versions of the tool to target different audiences. Two respondents were concerned about further multidisciplinary aspects by combining the work with prevention at a technical level, such as raising awareness and technological skills, while one respondent suggested working with the police in the future.

6.3.2.3 Theme groups B: What could be improved?

The themes related to how to improve the design were: inclusive presentation, editing content, and misinterpretation issues.

The concerns around the **inclusivity of the presentation** were mainly related to the use of colours in the themes which might not be suitable for people with a visual impairment. Another concern was shared by one respondent who described it as a personal opinion. This feedback requested adding a quotation on the importance of the intent to people with long-term conditions. Other changes suggested were presenting quotes about beneficial aspects of using the Internet by people with chronic conditions, such as using it for part-time employment, research, and advocacy. However, this was acknowledged by the respondent as a personal opinion that could only be used if present in this study's data.

In relation to **editing materials**, these could be divided into proofreading notes and styling suggestions. Some typos and grammatical errors were highlighted by some respondents. With regards to the style of presentation, most respondents thought there was too much text in the

poster, one respondent thought the booklet was short and another respondent thought the left alignment of text is better.

Some concerns about **misinterpretation** of findings were raised. In relation to qualitative findings, the question was about victim blaming part in relation to the Social Network Involvement theme (theme 5). It could be interpreted as an advice for victims to avoid being online. One respondent asked whether theme-based stories were real.

The other concern was about the complexity of statistics presented; the respondents asked to simplify the statistics. One respondent was confused whether the key statistics were from this study or from background information in the literature.

Table 41. *The themes emerging from the participants and gatekeepers on the health promotion tool and how they were addressed*

What went well (Themes A)	What to improve (Themes B)	How it was addressed
Approachable presentation 'The booklet is concise with bullet points under each title. Themed stories is a great way of giving real examples and has a bigger impact. Use of coloured font and lay out makes it different and visually pleasant to read.' Respondent S9 (supporter)	**Inclusive presentation** 'Various colours are not always suitable for those with visual problems' Respondent S2 (participant) 'If you have any quotes on the positive impact/importance of the internet for us I'd like to	• Official guidance on inclusive communication were revised. • Increased contrast • Used a black and white version • Used bold instead of colours. • White backgrounds were used.

'The booklet is relatively short, which should make it more accessible to people.' Respondent S7 (supporter) 'The poster is an easy infographic for seeing all the information at once' Respondent S12 (supporter)	see them used' Respondent S1 (supporter/participant)	• Added quotes about the use of the Internet before targeting.
Active participants' voice 'Highlighting the issue and sharing of real stories' Respondent S3 (participant) 'I really like this style of dissemination. Particularly using direct quotes from participants and showing the thematic analysis (I'm involved in similar research and it's given me the idea that we could also do this).' Respondent S1 (supporter) 'Sadly, as someone who staffs our 24 hour Helpline, the statements contained in the personal narratives are all too familiar to me. That said, I would acknowledge that such narratives are powerful tools in terms of raising awareness and giving those not affected some genuine insights into the nature and impact of such	**Editing content** 'I would recommend putting the theme-based stories, key themes, most of the quotes from victims, and some of the key statistics in the booklet and keep the poster minimal with the most important messages on there - i.e. what cyber-victimisation is, that it has a serious impact, and where people can get support' Respondent S5 (supporter) 'Too much wordy detail to read - I found I skim read some of the lengthier portions.' Respondent S8 (supporter) 'There are quite a few spelling and grammatical mistakes on both documents which makes them seem rushed rather than carefully prepared, as we know they would have	• The content was proofread. • Left alignment was used. • Statistics were simplified. • The poster was simplified and decreased test content.

victimisation.' Respondent S10 (supporter)	been. Both documents are summarising what came out of the surveys but there could be more about how people can seek support to resolve issues they may have experienced. We know you are asking organisations to give their details though.' Respondent S12 (supporter)	
Highlighting an important issue 'it's interesting and worrying' Respondent S4 (supporter) 'This is a very valuable and much needed resource' S6 (supporter) 'Having taken the time to read the material and having also solicited comments from colleagues, I would say that our feedback is entirely positive. We feel that as an awareness raising tool this is an excellent initiative.' Respondent S10 (supporter)	**Potential for misinterpretation** 'This stigma and oppression exists in our society in general, but the internet is where we can be found to be harassed. We even advertise our Chronic Illness Disability identity with hashtags. As your participant puts it, we're sitting ducks … The victim blaming aspect of your Social Network Involvement theme is important here. Depending on how you disseminate, I'm slightly concerned that the interpretation could be used in a similar way' Respondent S1 (supporter)	• The presentation of findings was simplified. • Support was offered.
Encouraging future work 'We are just starting our research project and it might be beneficial for us to discuss methodology issues with you' Respondent S1 (supporter/participant)	'Statistics are a bit hard to comprehend. Maybe simplify them somehow' Respondent S3 (participant)	

'This is a step in the right direction, it does need however to be followed up by laws protecting people without invading their right to privacy ART 8 Human Rights act' Respondent S2 (participant) 'it might also be useful to produce different resources for different audiences - for example one aimed at healthcare professionals outlining the impact and support they can provide, and another aimed at the public raising awareness and signposting people to the police & support services.' Respondent S5 (supporter) 'Suggest practical steps to combat vulnerabilities The theme of the poster in the future might Indicate basic IT skills. That would prevent 80% of hacks.' Respondent S11 (participant)		

6.3.2.4 Incorporating the input from the participants and gatekeepers

Following this feedback, several modifications were applied as shown in Table 40 and Appendices 29-30. The design was found to be accepted by the supporters and participants. One of the positive aspects was its pleasant presentation. Which confirms the use of

infographics and art in health promotion (Laverack, 2014b). One participant thought that the poster was easy. However, this was a controversial issue because other respondents thought the poster was too wordy. Thus, the majority was followed by minimising the text in the poster (Appendix 29) while preserving the information in the booklet (Appendix 30). In the literature, despite acknowledging the role of eye-catching graphic designs (Ninomiya, 2017), visual accessibility of graphic designs was not usually considered (Cornish et al., 2015). This created a gap between the intended information and the public use. The strength of this study is that the researcher is the designer, and with input from people involved the gap between the information and the audience was narrowed. Despite having one positive comment, the use of the colours was acknowledged to be inappropriate with people who have visual impairments. The priority was given to the input from the victims, hence this was changed.

With regards to accessibility, people with disabilities are excluded from health research directly or indirectly. Directly because of rigid inclusion criteria, or indirectly because of inaccessible tools. (Rios et al., 2016). In this study, the research design was flexible and alternatives were provided to the participants to facilitate participation, such as virtual interviewing, written interviews or phone. One participant with visual impairment experienced cyber-victimisation and was keen to reach the study by contacting a gatekeeper to fill the survey. Accordingly, to improve the design, the accessibility of the design was revised in accordance to the guidance provided by the Home Office Digital, designing for disability (Home Office Digital, 2016), and the guidance on accessible information formats (Office for Disability Issues, 2014b). Accessible research is done through, universal design, accommodation, and/or modification (Rios et al., 2016). In this research, the accommodation of the design for example by changing the colours and formats was used to ensure reaching wider audience.

The presence of real stories was a major strength that was endorsed in this tool. Story telling is an increasingly used tool in healthcare (Greenhalgh and Wengraf, 2008). The use of the lived-experience in health promotion is documented (Owens, 2008). Hence, the dissemination of the design with real stories was considered powerful and well-received. Hence, this bridged the gap in presenting the victim's perspective (Alhaboby et al., 2017b) and could be used in future work too.

The positive role of the internet was acknowledged in the literature review (chapter 2), and in the supportive online groups (section 3.6). This was not presented in the poster, however, in response to the feedback, the data was revised to ensure including this quote to demonstrate the importance of online communication which indirectly reflects the impact on communication in theme 3.

In response to the typing and grammar errors in the tool, proofreading was done. Changes in alignment were applied too in accordance with guidance (Home Office Digital, 2016). The poster was modified to be shorter, while keeping the details in the booklet. This was a controversial issue but the researcher followed the majority of opinions due to the importance of the role of gatekeepers in dissemination.

The interpretation of the findings was variable. The supporters' perspective who were experts in working with the victims was focused on dissemination, while the victim's perspective was focused on reassurance by finding other people narratives (Greenhalgh, 1999; Greenhalgh and Wengraf, 2008). Thus, the theme-based stories were kept in the booklet.

The confusion on statistics was acknowledged by the researcher. Because this study is mainly qualitative and focusing on the victims' perspective, the statistics in the poster were minimised to respond to the feedback from the respondents as co-researchers (International Collaboration for Participatory Health Research, 2013). Additionally, the detailed results were

provided in the booklet, and contact information were provided to those interested in further details.

The responses about how influential aspect of the work to direct future collaborations is important. It could be seen as a direct impact and a strength in this study in the area of health promotion. This included ideas to the work in prevention, influencing laws and working with the supportive channels. The work with the police was initiated earlier (Appendix 25). The multidisciplinary aspect in this work is also acknowledged for future collaborations (Appendix 24). Another strength is allowing supporters to provide their details to support people who go through this experience, which could be considered as an impact of this study. Especially that most of them are well-established organisations that can support people in need and influence changes.

There was a consensus on the importance of the dissemination of the results and the issue the design is highlighting. All of the supporters requested the final copy of the design and stated they will use it to support patients/victims. This shows the impact of this study which could be taken further by research and wider implementation to promote wellbeing.

6.3.4. Media articles

This aspect of disseminating was important to reach closed communities and the public. The research papers could not be accessible to these groups, hence communicating in short articles helped in awareness raising among the victims, as shared in Appendix 4.

6.3.5. Bedfordshire police

I provided expert support to Bedfordshire Police, as part of a bigger multidisciplinary project on cyber-harassment. I have looked at the documented cases of disability hate, and analysed the

patterns of cyber-disability hate cases. This was gathered in a detailed report and recommendations shared with the police (Appendix 25).

6.4. Conclusion

Cyber-victimisation of people with chronic conditions is prevalent and alarming, with devastating multi-level impact at different ages and under variable terminologies. Around one in every two people with long-term conditions in this study was victimised (45.39%), with 76.81% of the victims having a self-reported disability. There was a statistically significant relationship between cyber-victimisation and disability. From the perspective of the biographical disruption concept, the participants had continuous biographical working to cope with their long-term conditions, and cyber-victimisation was introduced to this vulnerable situation as an additional traumatic disruptive event. The impact included influencing the objective impairment, subjective illness, and the social representation as a sickness. This was through triggering significant fear and unplanned undesirable changes to the self-management plan. In total, 61.11% of victims reported that experiencing cyber-victimisation affected their self-management plan, with the highest impact on lifestyle changes, such as exercise, diet, avoiding triggers and avoiding excessive smoking or alcohol drinking. This was followed by changes to medications and follow up with healthcare professionals. In this study, 69% of victims perceived a worsened self-efficacy scale for the self-management of the health condition following cyber-victimisation. The interviews confirmed these effects and revealed biomedical, mental, multi-level, complicated and social impacts. Six themes emerged from the qualitative data, Biomedical Events (overall health - physical complaints), Impact on Mental Health (psychological and psychiatric effects - helplessness), Multi-level Impact (existing vulnerability - disruption and reprioritisation), the Impact of Complexity (complex situation - struggle for support), Social Network Involvement

(social isolation and victim blaming - controversial social support - misrepresentation of self), and Disability Discrimination (inclusion, culture and hate - tax and disability benefits).

In general, formal support was rated poor, with 24.53% of victims having spoken to their GPs received variable responses. The participating GPs thought that cyber-victimisation has both a mental and physical impact on people with chronic conditions, which raises concerns over online health forums support. Furthermore, GPs responses were influenced by individual variations.

This study pioneered this area in the UK, to set the baseline and build proper support for people with long-term conditions that is context-specific and condition-specific. Reaching a context-specific work could be achieved in future research. The study highlighted attitudes towards participation among the target population, engaging support groups who were highly concerned about the issue; these two points could be used to plan future research, for example, disability identity, people having rare conditions, females and online support groups role in support. Reaching a condition-specific work is achievable by using this work to identify possible conditions that were targeted (diabetes, COPS, depression, thyroid conditions, ME, MS, EDS) or those who are at risk of threatening impact, to tailor specific prevention and support by experts in the field. All conditions reported require attention and further investigation due to the potential impact upon victims despite the apparent low numbers of people affected. The findings were used for health promotion, which involved the participants and support groups in a harm-reduction approach, and encouraged action to influence change in the longer term. The findings were welcomed upon dissemination, and were considered important, accessible and influential. Eight support channels volunteered to supply their contact details to support victims through this research, and requested the final copy of the health promotion design for their use. Respondents suggested further changes in the style and addressing the needs of people with visual impairments, and these were further applied. This work has informed the UK legislation through

the House of Commons. Future participatory work, multidisciplinary collaboration and full engagement to mitigate this phenomenon and promote wellbeing are recommended.

6.5 Reflection

I consider reflecting on my own research as an important way to assess my work. The reflection on the research process is documented in the literature (Seale, Nind and Parsons, 2014), it includes the first ideas by the researcher before commencing the study, change in ideas throughout the research, and challenges faced throughout the process. To reflect on my own work, I have published a paper to discuss the challenges I faced during the recruitment process to assist the researchers in the field (Alhaboby et al., 2017a). However, there are other changes that occurred during this journey.

I began this research with a phenomenologically-informed approach (Giorgi, 2009), to consider people as experts in their own experiences. However, subconsciously I was still influenced by my medical background, the domination of the biomedical model in my area (Engel, 1979; Alonso, 2004). This was apparent in my frequent use of the terms ‘chronic diseases’ and ‘patient’. As the research progressed, I started learning from my own participants, they were more than ‘patients’ and more than ‘victims’, and my terminology could build unintentional power imbalance. Hence, I modified my terminology to call them people with long-term conditions. However, one activist in the field preferred to be called ‘disabled’ to reflect the role of culture presented in theme 6 on disability discrimination.

This study helped me to improve my own skills. For example, to get better responses during the recruitment process I enrolled in a course to learn about social media marketing, earning a

diploma (Appendix 4). This study also helped me to get more involved with closed communities, research colleagues and media. This work enabled me to network with other colleagues in the field in addition to temporary working with Bedfordshire Police to analyse Disability Hate Crime data (Appendix 25).

My medical background, and this research, assisted me to understand students with disability needs. During this research, I was teaching community health to students at the Faculty of Health and Social science, this was integral to my work because the focus of the module was marginalised groups. Additionally, I gave special attention to include students with disabilities, in my case, this was my successful Fellowship for Higher Education Academy (FHEA) application. I was also advised to share this experience with other departments. I also taught qualitative methods in health to a large cohort and the social identity theory in public health.

This study also allowed me to use my previous experience in participatory research. In particular, my previous work in East London employing community-based participatory research (CBPR) enabled me to be flexible, understand participants' needs, and allow as much participation as possible at this stage. It also helped me to incorporate my cross-cultural work on health promotion, due to my involvement in culturally sensitive health promotion campaigns.

As an author, this research has also informed my personal publications. One of my published novels is about discrimination against a person for being different from the surrounding society, due to being left-handed with dextrocardia. In another novel, I called for equality of marginalised groups, without differentiation between gender, socioeconomic status and health. In my latest publication (Mowdy, 2017; Murphy, 2017), which was shortlisted in the Guardian's best science fiction stories in 2016, the main character was living with a disabling syndrome and

labelled by people around him as having a special need, and most of his personal experiences were linked by his social network to his illness.

In this journey I went through a new experience by becoming a mother. I did not take any maternity leave. In spite of my clinical background, going through an eventful pregnancy, coping with the changes in life, and the stress to keep my work on track were all challenging aspects that I learned from. This got me closer to my participants' experiences, I was thinking about them, wanted to do my best to take their voices forward, they entrusted me with their experiences and I did not want to let them down.

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Appendices

Appendix 1: Ethical approval

University of Bedfordshire
Institute for Health Research
Putteridge Bury
Hitchin Road
Luton
Beds LU2 8LE

24 July 2015

Zhraa Alhaboby
Student number: 1417661

Dear Zhraa Alhaboby

Re: IHREC Application No: IHREC557

Project Title: Chronic Diseases Self-management and the Experience of Cyber stalking in the United Kingdom.

The Ethics Committee of the Institute for Health Research has considered your application and has decided that the proposed research project should be approved with no amendments.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely

Dr Yannis Pappas
Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

Appendix 2: NHS communication

University of Bedfordshire

Zhraa Alhaboby <zhraa.alhaboby@study.beds.ac.uk>

PhD study enquiry

Queries HRA (HEALTH RESEARCH AUTHORITY) <hra.queries@nhs.net> 17 June 2015 at 07:48
To: Zhraa Alhaboby <zhraa.alhaboby@study.beds.ac.uk>

ENQUIRY TO QUERIES LINE

Dear Zhraa Alhaboby

RE: Chronic Diseases Self-management and the Experience of Cyberstalking in the United Kingdom

Thank you for your email regarding whether your project should be classified as research requiring NHS Research Ethics Committee (REC) review.

We note that you have used the HRA's decision tools which have provided a decision regarding whether the proposed project is classified as research and whether it requires review by an NHS REC. We note that you are seeking confirmation of that decision.

The results obtained from the HRA's decision tools can be taken as an authoritative decision and are line with:

- The harmonised UK-wide edition of the Governance Arrangements for Research Ethics Committees (GAfREC), which came into effect on 01 September 2011;
- Research Governance Framework for Health and Social Care (Second edition, 2005)
- The National Research Ethics Service (NRES) leaflet, *Defining Research* and the algorithm *Does my project require review by a Research Ethics Committee?*.

The decision obtained from the decision tools should not be interpreted as giving a form of ethical approval or endorsement to your project on behalf the HRA. However, it may be provided to a journal or other body as evidence if required.

Where a journal or other body (including any NHS organisation) states that they will not accept the copy of the results page from the HRA decision tool as evidence you should ask them to contact the HRA directly through this queries line email address.

You should also be aware that:

- The decision tools only cover whether your project is classified as research and whether it requires review by an NHS REC. You are strongly advised to consider other approvals that may be required for your project.

- All types of study involving human participants should be conducted in accordance with basic ethical principles, such as informed consent and respect for the confidentiality of participants. Also, in processing identifiable data there are legal requirements under the Data Protection Act 1998. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation.

- If you have a specific query in relation to how to answer the questions asked by the decision tools please email hra.queries@nhs.net making the reason for your uncertainty explicit. Our advisors will need this explanation along with a screenshot of the decision tools and a copy of your protocol or one page (1,000 word max) summary in order to clarify the outcome.

Regards
Queries Line
REF 07/07

The Queries Line is an email-based service that provides advice from HRA senior management, including operations managers based in our regional offices throughout England. Providing your query in an email helps us to quickly direct your enquiry to the most appropriate member of our team who can provide you with an accurate written response. It also enables us to monitor the quality and timeliness of the advice given by the HRA to ensure we can give you the best service possible, as well as use queries to continue to improve and to develop our processes.

Health Research Authority
Ground Floor, Skipton House

Appendix 3: DBS communication

Zhraa Alhaboby <zhraa.alhaboby@study.beds.ac.uk>

E061502079-172368
1 message

Customer Services <CustomerServices@dbs.gsi.gov.uk> 25 June 2015 at 16:28
To: Zhraa Alhaboby <zhraa.alhaboby@study.beds.ac.uk>

Dear Ahraa,

Thank you for your enquiry.

To begin I should advise that the role of the Disclosure and Barring Service (DBS) is to help employing organisations in England and Wales make safer, more informed, recruitment decisions.

The *entitlement* for an employer, voluntary organisation, or licensing organisation to ask an individual to apply for a Disclosure and Barring Service (DBS) check, at either Standard or Enhanced level, is set out in legislation.

Eligibility – legal entitlement to request a check - is based upon the nature of the duties for the specific position. To be eligible for a DBS check a position must be:

- Listed in the Rehabilitation of Offenders Act (ROA) 1974 (Exceptions) Order 1975 – this entitles the position to a Standard level check; and if
- Prescribed in The Police Act 1997 (Criminal Records) Regulations entitles the position to an Enhanced level check.

Below is a guide to Eligibility; in effect a list of professions, offices and employment roles that meet legal entitlement to be DBS Checked.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/143666/eligibility-guidance.pdf

Appendix 4: Research activities and certificates

- Has 10 publications in the past 24 months, 7 accepted and 3 under review.
- Disability Hate Crime Network - group member (Sep 2015)
- Attended a workshop on hate crime against disabled people at King's College London and awarded certificate with CME points. (March 2016)
- Studied Diploma in Social Media Marketing to use the skills in recruitment for this study. (July 2016)
- Enrolled in the Professional Teaching Scheme (PTS) and received Fellowship with the Higher Education Academy (FHEA). (July 2016)
- Attended the event "Managing long-term conditions: Insights from research and practice" and got a continuing professional development certificate, organised by Health Psychology in Public health Network (HPPHN).
- Submission of University bid 2015-2016 to improve student experience by combating cyberstalking/online harassment on campus.
- Working with the National Centre for Cyberstalking Research team on Electronic Communication Harassment Observation (ECHO) project.
- Examined hate crime cases in Bedfordshire, and wrote a detailed report on cyber-disability hate crimes for the Police.
- Successfully completed and certified with the course titled "Improving Healthcare through Clinical Research" at the National Institute for Health Research (INHR). (November 2016)
- Was invited by the House of Commons to submit written evidence to online abuse enquiry, as an expert in the field of cyber abuse of people with chronic conditions. (Jan 2018)
  https://www.parliament.uk/business/committees/committees-a-z/commons-select/petitions-committee/inquiries/parliament-2017/online-abuse-17-19/

Media engagement

- Published an opinion piece in GP news forums addressing cyber-victimisation and the role of GPs. (August 2016)
  https://www.gponline.com/cyber-abuse-why-gps-ideally-placed-help-patients-suffering-harassment/article/1403804

- Was invited to write about the cyber-victimisation of people with disabilities in the Disabled World news: https://www.disabled-world.com/disability/cyber.php
- Contributed an article on the cyber-victimisation of people with chronic conditions to Disability Horizons. (Feb 2017)
- Was invited to write a guest post about cyber-victimisation and chronic conditions, in response to the systematic review. (Dec 2017) https://openforest.net/research-looks-cyber-victimization-people-chronic-conditions-disabilities/
- Helped in recognizing the Spoon Theory publicly: https://en.wikipedia.org/wiki/Spoon_theory
- Was invited to write a guest post in the same blog above about cyber-victimisation and chronic conditions, in response to the health promotion aspect. (Jan 2018)
- Contacted by the Guardian journalists to publish the results with them. (Dec 2017)

Appendix 5: Quality assessment of the studies included in the systematic review

Study	Stage 1: Critical appraisal of risk of bias in included studies*						Stage 2: Cyber-victimisation-score **	Assessment outcome
	Study design appropriate for objectives	*Study population (Source, sampling strategy, sample size, eligibility criteria, non-respondents)*	*Comparison group acceptable*	*Completeness of data*	*Soundness of outcome assessment*	*Control for confounders*		
(Kowalski and Fedina, 2011)	0	++ (sample size and eligibility criteria)	0	N/A	0	+	30 ***CV criteria: fulfilled	Moderate
(Sheridan and Grant, 2007)	0	+ (exclusion not clearly justified e.g occasions, delusional cases)	0	0	0	0	38 CV criteria: fulfilled	Strong
(Didden et al., 2009)	0	+ (one source, insufficient description of setting and exclusion criteria)	+	0	+ (instrument used)	0	26 CV criteria: partial	Moderate
(Sofronoff et al., 2011)	+ (themes came from parents of victims)	++ (only parents of victims included)	0	0	+ (themes endorsed by only 2 parents)	0	20 CV criteria: partial	Moderate

(Mueller-Johnson et al., 2014)	0	0	0	0	+ (impact indirectly discussed)	0	40 CV criteria: fulfilled	Strong
(Wells and Mitchell, 2014)	0	+ (inclusion and non-respondents)	0	N/A	0	0	32 CV criteria: partial	Strong
(Yen et al., 2014)	0	+ (excluded a number of conditions, only males included)	++ (no comparison, only victim/offender status reported)	0	0	0	30 CV criteria: partial	Moderate
(Gibson-Young et al., 2014)	0	0	0	+ (unclear numbers	+ (not clear reporting)	0	27 CV criteria: partial	Moderate
(Annerbäck et al., 2014)	0	+ (unclear justification of including particular diseases)	0	0	++ (chronic diseases reported collectively, cyber-victimisation estimate missing)	0	31 CV criteria: partial	Moderate
(Fridh et al., 2015)	0	0	0	0	+ (unclear outcome in relation to diseases)	0	32 CV criteria: partial	Strong

* List adopted from (Fowkes and Fulton, 1991; Gyorkos et al., 1994) focusing on items related to cross sectional studies, ++ =major problem, +=minor problem, 0=no problem, NA= Not Applicable/not reported.

** STROBE score out of 42 tailored to quality of cyberbullying reports adopted from (Von Elm et al., 2007).

***CV: Cyber-victimisation, fulfilled when the study reported clear instrument and cut-offs, partial reporting of cut-offs or problem with tools.

Appendix 6 Summary of critical findings in this review on cyber-victimisation of people with chronic conditions

Study	Discipline	Country	Study design	Sample size with chronic disease (Source sample)	Age (years)	Conditions covered	Online victimisation estimate and duration	Relationship between online victimisation and chronic illness	Impact
(Sheridan and Grant, 2007)	Psychology	UK 53.1%, USA 36.2, Australia	Cross-sectional	N/A	10-71	• Disability	11.9% of pure cyberstalking cases. Minimum of 4 weeks	Secondary outcome, suggested risk	• Comparable to traditional stalking • (fear, anxiety, agoraphobia, distrust, depression, weakness, physical injury self-harm, nausea, appetite changes, sleep disturbance, weight changes headache, aggression, paranoia)
(Didden et al., 2009)	Psychology	Netherlands	Cross-sectional	114	12-19	• Intellectual disabilities,	*Cell phone:* 2-18% in past 3 months *the Internet:* 14-29%	Vulnerability and being an offender too	• Depressive symptoms • Low self esteem • Emotional distress

						• Borderline IQ (less than 85), • Developmental disabilities, • Behavioural and emotional problems, • Pervasive Developmental Disorder, ADHD	Once per month *Or* 5-12% more than once a week		
(Sofronoff et al., 2011)	Psychology	Australia	Mixed-Methods	133 *parents	6-16	Asperger's syndrome	Theme endorsed by 2.4% of parents out of 82 responses	Social vulnerability	• Anxiety • Behavioural problems
(Kowalski and Fedina, 2011)	Psychology	USA	Cross-sectional	42	10-20	• ADHD • Asperger's syndrome	21.4% Past two months	Vulnerability and being an offender too	• Anxiety • Depression • Low self esteem
(Wells and Mitchell, 2014)	Social work	USA	Cross-sectional	167 (drawn from 1,560)	10-17	Special education Physical disability	Harassment 14% Distressing Harassment 8% Sexual solicitation 14%	Vulnerability	Depression Distress Substance abuse

							Distressing solicitation 7% Past year		
(Mueller-Johnson et al., 2014)	Criminology	Switzerland	Cross-sectional	360 (drawn from 6,749)	15.4 mean	Physical disability	23.5% lifetime	Vulnerability	N/A
(Yen et al., 2014)	Medicine/ Psychiatry	Taiwan	Cross-sectional	251	11-18	ADHD, Oppositional defiant disorder, Autism Spectrum, Tic disorders	19.1% Last year	Vulnerability and being an offender too	Depression Suicide Anxiety
(Gibson-Young et al., 2014)	Health sciences	USA	Cross-sectional	823 (drawn from 6,212)	Less than 15-18+	Asthma	17% Past year	Vulnerability	Depressive symptoms
(Annerbäck et al., 2014)	Public health	Sweden	Cross-sectional	413 (drawn from 5,248)	13-15	Impaired hearing, vision or motor function, Dyslexia, ADHD, Asthma, Diabetes, Epilepsy, Allergy, Intestinal disease	*8.5% (*33.5 % of all bullied children with disability/chronic disease) Past 2 months	Vulnerability	Poor health Mental health problems Self-harm
(Fridh et al., 2015)	Public health	Sweden	Cross-sectional	762 (drawn from 8,544)	12,15, 17	Impaired hearing, Impaired vision, Reading/writing disorders, Dyslexia, ADHD, Other	32.7% once 41.5% several Girls 28% once 35% several Past year	Vulnerability (covariate)	Subjective health complaints

Appendix 7: Identifying cyber-victimisation cases and terminology used in the systematic review

Study	Defining cyber-victimisation	Terminology used
(Sheridan and Grant, 2007)	• Harassed via the Internet or received unsolicited emails.	Harassment via the internet
	• Stalking that originated online and remained solely online for a minimum of 4 weeks. Stalking is identified by repetition (10 occasions or more) and persistence (minimum 4 weeks or more).	Cyberstalking
(Didden et al., 2009)	• Electronic form of bullying using electronic means of communication (cell phone or the Internet) • Bullying is an aggressive act by an individual or a group that is repeated over time and intentional against victims who can not defend themselves easily.	Cyberbullying
(Kowalski and Fedina, 2011)	• Bullying through email, instant messaging, chartrooms, webpages, receiving digital images or messages to phone. (Recognising bullying act as a verbal, physical or socially hurtful things that is repeated over time, with power imbalance, and on purpose)	Cyberbullying Or electronic bullying
(Mueller-Johnson et al., 2014)	• Subtype of non-contact sexual victimisation. • Clear sexual harassment or molested during an online communication (chatting, MSN, Netlog).	Cyber-victimisation

(Wells and Mitchell, 2014)	Being a target of online harassing behaviour in the past year, if someone used the internet to threaten, embarrass or post online messages about the victim, or the victim reporting feeling worried because of someone bothering him/her online.	• Online victimisation • Online harassment
	Unwanted requests for sexual information or acts, or talking about sex online.	Sexual solicitation
(Yen et al., 2014)	• Bullying using electronic venues (Email, blog, Facebook, twitter, Plurk). • Posting mean or harmful things, pictures or videos or spreading rumours online.	Cyberbullying
(Gibson-Young et al., 2014)	Electronically bullied in the past 12 months. (Bullying is an aggressive, intentional, electronic contact, repeated, victim can not defend self)	• Cyberbullying • Electronic bullying • Bullying in cyberspace
(Annerbäck et al., 2014)	• Harassment or violation via the Internet or mobile phones, self-reported in past 2 months. • A form of indirect bullying. (Bullying -also known as mobbing- is identified as the use of power to control others or cause distress.)	• Cyberbullying • Cyberharrasment
(Fridh et al., 2015)	Violation or harassment involving cellphone or the Internet such as Facebook, email, MSN, text messages in the past 12 months	• Cyberharrasment • Cyber-victimisation

Appendix 8: Identifying chronic conditions and disabilities, and terminology used in in the systematic review

Study	Identifying chronic illness/disability	Terminology used
(Sheridan and Grant, 2007)	Self-reported by victims.	Disability
(Didden et al., 2009)	Attending schools for special education with an IQ of at least 50 and ability to read.	Intellectual and developmental disabilities
(Kowalski and Fedina, 2011)	Pre-existing clinical diagnosis, attending summer camps for youth with ADHD and/or Asperger's syndrome.	Special needs
(Mueller-Johnson et al., 2014)	Self-reported physical disability that is congenital, secondary to illness or non-specified, resulting in limiting body functions.	Physical disability
(Wells and Mitchell, 2014)	Received special education or have a medical or physical health condition that interferes with activities, as reported by caregivers.	Disabilities
(Yen et al., 2014)	Recruited from outpatient clinics with diagnosis based on DSM IV criteria, psychiatric interviews, participants' clinical observations, medical history from parent, use of medications, symptoms severity or having combined illness.	ADHD and comorbidities
(Gibson-Young et al., 2014)	Self-reported, diagnosed by a doctor or a nurse and still experiencing it.	Asthma
(Annerbäck et al., 2014)	Self-reported severe impaired hearing vision or motor function, severe dyslexia, severe or mild ADHD, severe Asthma, diabetes, epilepsy, allergy, intestinal disease	Chronic disease or disability
(Fridh et al., 2015)	Self-reported, having any of : hearing disability, visual impairment that can not be corrected by glasses or contact lenses, reading or writing disability, Dyslexia, ADD, ADHD, or orthopaedic conditions.	Disability

Appendix 9: Systematic review search strategy

Components	Search 1	Search 2	Search 3	Search 4
Component 1: “cyberstalking”, “cyberharrasment”, “cyberbullying” OR (“cyber”, “online”, “internet”, “mobile” AND “stalking”, “harassment”, “bullying”, “discrimination”, “victim*”, “hate crime”)	“cyberstalking”, “cyberharrasment”, “cyberbullying”	“cyberstalking”, “cyberharrasment”, “cyberbullying”	(“cyber”, “online”, “internet”, “mobile” AND “stalking”, “harassment”, “bullying”, “discrimination”, “victim*”, “hate crime”)	(“cyber”, “online”, “internet”, “mobile” AND “stalking”, “harassment”, “bullying”, “discrimination”, “victim*”, “hate crime”)
Component 2: “disab*” “special need” OR (“chronic”, “long term” “ long standing” “lifelong” AND “disease”, “condition”, “illness”, “sickness”, “disorder”, “disab*”, “impairment”, “morbidity”, “co-morbidity”, **“**health problem”)	“disab*” “special need” OR (“chronic”, “long term” “ long standing” “lifelong” AND “disease”, “condition”, “illness”, “sickness”, “disorder”, “disab*”, “impairment”, “morbidity”, “co-morbidity”, **“**health problem”)	-	“disab*” “special need” OR (“chronic”, “long term” “ long standing” “lifelong” AND “disease”, “condition”, “illness”, “sickness”, “disorder”, “disab*”, “impairment”, “morbidity”, “co-morbidity”, **“**health problem”)	-
Component 3: “diabetes”, “heart”, “cardiovascular”, “COPD”, “pulmonary”, “epilepsy”, “psoriasis”, “bowel disease”, “syndrome”, “Crohn’s”, “Ulcerative colitis”, “asthma”, “eczema”, “mental health”, “cancer”, “arthritis”, “sclerosis”, “fibromyalgia’’, “palsy”, “skin”, “hormone”, “thyroid”,	-	“diabetes”, “heart”, “cardiovascular”, “COPD”, “pulmonary”, “epilepsy”, “psoriasis”, “bowel disease”, “syndrome”, “Crohn’s”, “Ulcerative colitis”, “asthma”, “eczema”, “mental health”, “cancer”, “arthritis”, “sclerosis”, “fibromyalgia”, “palsy”, “skin”, “hormone”, “thyroid”, “allergy”,	-	“diabetes”, “heart”, “cardiovascular”, “COPD”, “pulmonary”, “epilepsy”, “psoriasis”, “bowel disease”, “syndrome”, “Crohn’s”, “Ulcerative colitis”, “asthma”, “eczema”, “mental health”, “cancer”, “arthritis”, “sclerosis”, “fibromyalgia”, “palsy”, “skin”, “hormone”, “thyroid”, “allergy”, “fever”, “ADHD”,

“allergy”, “fever”, “ADHD”, “attention deficit”, “depression”, “hemiplegia”, “paraplegia”, “quadriplegia”, “autism”, “SLE”, “lupus”, “PCO”		“fever”, “ADHD”, “attention deficit”, “depression”, “hemiplegia”, “paraplegia”, “quadriplegia”, “autism”, “SLE”, “lupus”, “PCO”		“attention deficit”, “depression”, “hemiplegia”, “paraplegia”, “quadriplegia”, “autism”, “SLE”, “lupus”, “PCO”
Total results: 2,915	**602**	**1,399**	**480**	**434**

Appendix 10: The potential risks identified in this study and mitigation actions

Identified Risks	Likelihood	Potential Impact	Risk Management
Risk of causing distress when discussing a sensitive topic during interviews.	Medium	***Participants*** Psychological and emotional harm ***Researcher*** -Distress resulting from listening to narrative during an interview or during analysis. -Anxiety from anticipating distressing participants.	Explaining the study's focus verbally and written in participant information sheet and consent form. Participants have the right to skip questions, postpone interview or to withdraw without giving a reason. Provide general advice, contacts of support agencies, and a copy of the e-book "A Practical Guide to Coping with Cyberstalking" Debriefing with the research team and set intervals between interviews.
-Practical issues (timing and location). -Risk of being followed by the harasser in cases of "ongoing" harassment.	Medium	***Participant*** Psychological and/or physical harm ***Researcher*** Psychological and/or physical harm	Conducting interviews in a neutral public place such as universities or offering online interview via Skype. Interviews will be during University working hours 9 am to 5 pm. Giving the time, place expected return time from the

			interview to supervisors and NCCR team.
Data storage and disseminating findings.	Low	***Participant*** Risk of being identified.	Data will be completely anonymous, confidential and stored in accordance with Data Protection Act 1998. Written consent for group reporting of anonymised findings.
Receiving information that raises concerns about participant's safety or deteriorating health condition.	Medium	***Participants*** Physical or psychological harm that requires immediate attention. ***Researcher*** Anxiety in dealing with ethical dilemma and respecting confidentiality.	Depends on researcher's judgment and the seriousness of risk to the participant. The researcher will look for advice from supervisors who are cyberstalking and healthcare professionals, and each case will be dealt with individually.
Risk in interfering with GPs work and relation with patients.	Low	***Participants (GP)*** Anxiety in talking about patients' information.	No personal data will be gathered about GPs or their patients, and anonymous answers will be collectively analysed and reported
Risk of being targeted	Low	***Researcher*** Psychological and/or physical harm	Using University email only, and strict privacy settings in personal accounts. Keeping professional communication with participants.
Researcher's position and medical background	low	***Participant*** Influencing participants' attitude toward their management plan.	The researcher will answer only general questions related to health, while questions from patients related to the personal management plan will be advised to be shared with their physicians

Appendix 11: Survey questions

The Self-management of Chronic Conditions and the Experience of Cyber-victimisation in the United Kingdom

Self-completed Online Questionnaire

Pre-screen

Are you 18 years old or older?

Yes → Continue

No → Thank you for accessing this page, unfortunately, you are ineligible to participate in our study.

Do you live in the UK?

Yes → continue

No → Thank you for accessing this page, unfortunately, you are ineligible to participate in our study.

Do you have a long-standing medical condition/illness or disability that requires monitoring, lifestyle changes and/or taking medications?

(By long-standing we mean anything that has affected you over a period of at least 3 months or that is likely to affect you over a period of at least 12 months).

Yes → continue

No → Thank you for accessing this page, unfortunately, you are ineligible to participate in our study.

The research team is based at the National Centre for Cyberstalking Research (NCCR) and the Institute for Health Research (IHR) in the University of Bedfordshire. Contact address nccr@beds.ac.uk

General information and guidance

The research team of this study is based at the National Centre for Cyberstalking Research (NCCR) and the Institute for Health Research (IHR), University of Bedfordshire. In this study, we are interested to find out about your experience in living with a long-term condition in

addition to your online experiences including any form of negative communication (via the Internet, social media, phone calls or messages) such as harassment/stalking/bullying/discrimination/disability hate crime. We are also interested to know how you do/did cope with it. We understand that stalking/harassment/hate crimes can be a distressing experience, therefore the information you provide will help us to further understand this phenomenon in order to improve the support provided to victims in general and chronically ill individuals in particular.

This questionnaire is voluntary, it represents the first stage of this study. Completing this questionnaire will take approximately 10-15 minutes. If you start the questionnaire and feel that you do not want to complete it, you are absolutely free to withdraw at any point. Due to the limited knowledge about the experience of online harassment in relation to long-term conditions we are trying to cover as much information as possible.

The questionnaire consists of 4 sections, the questions are general questions about you, your health condition, your experience with negative online communication, and the support gained. Please note that ALL your answers will be completely anonymous and will be kept confidential with no means that can be traced to your identity. Responses will be analysed and group results will be reported to the National Centre for Cyberstalking Research (NCCR) at the University of Bedfordshire. Findings will be used to increase the awareness and improve the support for victims.

Please tick the following boxes after reading the information.

I confirm that I have read and understood the above information. ☐

I understand that my participation is voluntary and anonymous and that I am free to withdraw at any time without giving any reason.
☐

I agree to take part in the above study
☐

Contact details

If you are interested in further information or to complain please contact: nccr@beds.ac.uk

Section A: Demographic information

Please fill the following information:

1) **Gender**
   a. Female
   b. Male
   c. I don't want to specify

2) **What is your ethnic group? (Choose one option that best describes your ethnic group or background)**

Ethnic group	**Tick if applies**
White	
English / Welsh / Scottish / Northern Irish / British	
Irish	
Gypsy or Irish Traveller	
Any other White background, please describe ……	
Mixed / Multiple ethnic groups	
White and Black Caribbean	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed / Multiple ethnic backgrounds, please describe ……	
Asian / Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	
Any other Asian background, please describe ……..	
Black / African / Caribbean / Black British	
African	
Caribbean	
Any other Black / African / Caribbean background, please describe …….	
Other ethnic group	
Arab	
Any other ethnic group, please describe ……	

3) **Do you consider yourself to have a disability?**
   a. Yes
   b. No
   c. I don't want to specify

4) **Age in years** …….
5) **What is your religion?**
   a. No religion
   b. Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
   c. Buddhist
   d. Hindu
   e. Jewish
   f. Muslim
   g. Sikh
   h. Any other religion, please describe …….

6) **Which of the following options best describes how you think of yourself?**
   a. Heterosexual or Straight
   b. Gay or Lesbian
   c. Bisexual
   d. Other
   e. Prefer not to say

7) **Current area of residence**
   a. England, please specify county ……..
   b. Wales
   c. Scotland
   d. Northern Ireland
8) **Employment**
   a. Full time employed
   b. Part-time employed
   c. Self-employed
   d. Student
   e. Retired
   f. Unemployed
9) **Occupation**

a. Manager
b. Professional, please specify ……
c. Technician or associate professional
d. Clerical support worker
e. Service and sales worker
f. Skilled agricultural, forestry or fishery worker
g. Craft or related trades worker
h. Plant and machine operator or assembler
i. Armed forces occupations
j. Other, please specify ……

10) Section B: Your health condition

11) Do you have a long-standing medical condition/illness that requires monitoring, lifestyle changes and/or taking medications?

By long-standing we mean anything that has affected you over a period of at least 3 months or that is likely to affect you over a period of at least 12 months.

Yes

No → Thank you for participating, the rest of questions do not apply to you.

12) If your answer is yes, please specify your current medical condition, by ticking any option which describes your condition (you can choose more than one option)

Condition	Tick if you have it	Duration (years)	Duration (months)
Asthma			
Diabetes Mellitus type I			
Diabetes Mellitus type II			
Cancer			
Chronic Obstructive Pulmonary Disease (COPD)			
Chronic renal disease			
Heart disease			
Inflammatory Bowel Disease (Ulcerative Colitis or Crohn's disease)			
Eczema			
Epilepsy			
Multiple sclerosis			
Rheumatoid arthritis			
Thyroid disease			
Other, specify ……..			

13) If you have more than one condition, which one concerns you most?

……..

Notes to answer this question:
***if you have **only one condition** then please write it down**.**
****Please note that the **next questions** will be corresponding to the condition you state in your answer here.

14) What was your age when first diagnosed? ……

15) Who diagnosed your condition?

a. By doctor in the UK
b. By doctor abroad
c. Self or family diagnosis
d. I don't know
e. Other ----------

16) What was your first reaction when diagnosed?

a. It was expected/ or had no fear or distress
b. Slight fear/distress
c. Moderate fear/distress
d. Extreme fear/distress

17) What does your management plan include? (You can choose/tick more than one option)

Management options	**Tick here if it is part of your management plan**
Lifestyle-related	
a. Healthy eating	
b. Avoiding particular type of food	
c. Avoiding particular triggers that exacerbate your illness	
d. Avoiding smoking	
e. Avoiding excessive drinking	
f. Exercise/physical activity	
g. Other lifestyle changes	
Medication-related	
h. Regular medications	
i. Medications on need (prescription)	
j. Medications on need (Over The Counter)	
Follow up related	
k. Self-monitoring at home (example: blood sugar)	
l. Regular follow up with GP	
m. Regular follow up with specialist	
n. Regular follow up with other healthcare professionals	
o. Physiotherapy	
p. Counselling sessions	
q. Regular lab tests	
r. Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture)	
s. Other management, specify …….	

Section C: Your experience of online harassment

18) Do you consider yourself to be a victim of cyberstalking/online harassment?

a. Yes
b. No
c. I don't know

19) Have you ever experienced that someone unwantedly contacted you repeatedly (more than once) via the Internet such as email, chartroom, online forum, social network, mobile phone message, or other electronic means and used it to harass, insult, embarrass, or spread lies about you?

Yes

No → Thank you for participating, the rest of questions do not apply to you.

If your answer is yes, then it is assumed that this could be an online harassment experience. Please answer the following questions about this experience to the best of your knowledge.

20) Do/did this experience cause you distress or fear?

a. No fear
b. Slight fear
c. Moderate fear
d. Extreme fear

21) What was your age when you first experienced online harassment?
…….

22) How does/did the harasser contact you? Please tick all that applies.

Mean	Never	Once per day or more	More than three times per week	Once per week	Once per month	Less than once a month
Email						
Facebook						
Twitter						
Instagram						
Youtube						
Health forums						
Blogs						
Text messaging						
Other, specify ……..						

23) What is/was the duration of cyberstalking/ online harassment?

a. Less than 2 weeks
b. From 2 weeks to 4 weeks
c. From 5 weeks to two months
d. From 3 months to one year
e. More than a year

24) Which of the following best describes your primary harasser/harasser? Please tick all that applies.

Relationship	Tick here if applies
Close friend	
Family	
Ex-partner	
Work colleague	
Professional contact	
Acquaintance	
Stranger	
Unknown (I am not sure about the identity of my harasser)	
Other, specify …….	

25) How many unrelated, separate campaigns of online harassment have you experienced? (how many times did you experience online abuse by different harassers?)

……

26) Are you still being stalked/harassed?

Yes No

Section D: In this section we are interested in learning about your experience in online harassment in relation to your medical condition

27) In a scale of 10, please answer the following questions about your condition BEFORE and AFTER experiencing cyberstalking/online harassment:

The 0 in the scale means (not confident at all) and the 10 means (totally confident)

Question	BEFORE experiencing cyberstalking/online harassment Score (0-10)	AFTER experiencing cyberstalking/online harassment Score (0-10)
How confident were you that you can keep the fatigue caused by your disease from interfering with the things you want to do?		
How confident were you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?		
How confident were you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?		
How confident were you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?		

How confident were you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?		
How confident were you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?		

28) Do/did you feel that the experience of online harassment affected your management plan?

Yes

No → Please go to question 30

29) If your answer is yes, which aspect of this plan was affected?

Management options	**Tick here if it is part of your management plan**
a. Lifestyle-related	
Healthy eating	
Avoiding particular type of food	
Avoiding particular triggers that exacerbate your illness	
Avoiding smoking	
Avoiding excessive drinking	
Exercise/physical activity	
Other lifestyle changes	
b. Medication-related	
Regular medications	
Medications on need (prescription)	
Medications on need (Over The Counter)	
c. Follow up related	
Self-monitoring at home (example: blood sugar)	
Regular follow up with GP	
Regular follow up with specialist	
Regular follow up with other health care professionals	
Physiotherapy	
Counselling sessions	
Regular lab tests	
d. Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture)	
e. Other management, Specify ……	

30) Please tick the sentence that describes how your condition was affected by cyberstalking:

Statement	Never	rarely	sometimes	Frequently	Always
Being harassed made me ignoring my medications					
My health never got back to how it was before being harassed.					
Being harassed made me too tired to do exercise.					
Being harassed made me too scared of outside exercise.					
Being harassed affected my GP follow up appointments.					
Being harassed made me too scared to attend my appointments.					
Being harassed affected my appetite and eating.					
Being harassed affected my self-monitoring at home.					
Being harassed made me taking more medications than usual.					
Being harassed made me taking painkillers more than usual.					
Being harassed made me taking prescribed drugs.					
Being harassed made me start smoking or smoking more than usual.					
Being harassed made me start drinking alcohol or drinking alcohol excessively.					
My treatment was the same but I felt worse after being harassed.					
My treatment was the same but my lab tests deteriorated after being harassed.					
After being harassed my treatment was the same but my doctor says I am not doing well.					
After being harassed my treatment was the same but my family/friends think I am not doing well.					
If you have other comment that best describe your condition, please write it down ……					

31) Do you consider that having this illness is related to your experience of being harassed online?

Yes

No → Please go to question 32

32) If yes, please specify how.

……

Section E: Support and response

33) Have you received any support to help you cope with online harassment?

Yes

No → Please go to question 32

34) If yes, who or where did you get support from?

Please tick all that applies and rate the effectiveness of support

Support	**Tick if applies**	**Rate effectiveness of support (0-4) 1=poor 2=fair 3= good 4= very good**
Family		
Friends		
Victim support groups		
Healthcare professional, please specify ……		
Police		
Other, specify ……..		

35) Did you talk to your GP about your online harassment experience?

Yes → Please go to question 36

No → Please go to question 35

36) If no, please specify why? ……..

37) If yes, what was the advice given to you? …….

38) What would you rate the effectiveness of support given by your GP?

a. Very good
b. Good
c. Fair
d. Poor

39) Please tell us if there was anything that you feel could have helped you to get a better support from your doctor

……

Next phase recruitment:

We would like to know more about your experience, if you are interested in this study and feel that you can share more information on your particular experience, we may invite you to the next stage of this study which is a voluntary in-depth interview. Please note that you can withdraw at any point even if you state here that you want to participate.

Please tick if you are interested in participation in the next stage. ☐

Please give us your contact information (which will be kept confidential) to contact you about the next stage. Your email ……..

Further information and description on the next stage will be sent to you if you are willing to participate.

To contact us for further information or to complain please email: nccr@beds.ac.uk

Thank you for your time, it's really appreciated!

Appendix 12: Interview guide

The Self-management of Chronic Conditions and the Experience of Cyber-victimisation in the United Kingdom

Semi-structured interview

Hi, thanks for coming and nice meeting you. My name is Zhraa, I am a researcher at the Institute for Health Research at the University of Bedfordshire.

Thank you for sparing some time in your schedule to meet with me. The interview consists of a set of 10 questions about your experience of cyberstalking while living with a chronic condition. The structure of the interview is not strict and you are allowed to talk freely about your condition.

Can you please introduce yourself?

1- Please start by telling me about your long-term condition.

Prompts:

- Diagnosis
- Age of onset
- Management

2- How did you react to the diagnosis of your condition?

Prompts:

- First response
- What did you do next?
- Coping and self-management
- *How do you feel about it <u>now</u>?*

3- What about your experience of online harassment, could you please tell me how it began?

Prompts:

- Means/methods (email, health forums, Facebook, instant messaging, or other means)
- Relationship with the harasser
- Examples

4- What was your first reaction when you realised you are being harassed online?

- First response emotional/physical
- What did you do next?
- Coping

- *How do you feel about it <u>now</u>?*

5- What do you think is/was the motive of your harasser?

Prompts:

- Why were you harassed?
- Any relation to having long-term condition?

6- What kind of effects online harassment had on you?

Prompts:

- Psychological well being
- Physical well being
- Economical

7- How do/did you manage your chronic condition before, during/after being harassed online?

Prompts:

- Self-management plan
- Perceived changes (Medications/lifestyle/appointments)

8- Please tell me about any formal or informal support you received during or after being harassed online.

- From whom?
- Effectiveness
- Spoken to GP?

9- Are there any actions that you feel would have helped you if they were available to you?

- What else could have helped you cope with the situation?
- How to improve GP support?

10- Do you want to add anything that is related to your experience of cyberstalking/online harassment while having a long-term condition that I did not already ask you about?

Thank you for your time and cooperation.

Appendix 13: Consent form

Long-term Conditions and the Experience of Cyber-victimisation in the United Kingdom

Interview Consent Form

The above study explores the impact of the experience of cyber-victimisation on the self-management of chronic conditions. Please read the attached information sheet before signing this form to ensure that you understand the purpose of this research and happy to participate. Please note that every information you share will be confidential and will be kept anonymous with no means to be traced to your identity. If you prefer Skype interview please return this document via email.

Before taking part in this research, could you please read the following statements carefully and sign a tick next to each statement:

Consent Checklist

- I have read and understood the information sheet for the above study. ☐
- I have been given the opportunity to ask questions about the study and I am happy with the answers. ☐
- I understand that participation is voluntary and I can withdraw at any time without giving a reason. ☐
- I understand that the information I provide will be treated with confidence and my name will not be identified in any reports or publications arising from this research. ☐
- I understand that all data is stored and processed in accordance with the Data Protection Act 1998. ☐
- I agree to take part in this study. ☐

Participant:

_____ _____ _____

Name of Participant Signature Date

Researcher:

_____ _____

_____

Name of Researcher Signature Date

Appendix 14: The participant information sheet

University of Bedfordshire

Long-term Conditions and the Experience of Cyber-victimisation in the United Kingdom

Participant information sheet

Introduction

This study aims at exploring the impact of online harassment on individuals living with long-term conditions or disabilities in the UK and how do they cope with it. The research team is based at the National Centre for Cyberstalking Research (NCCR) and the Institute for Health Research (IHR) at the University of Bedfordshire.

You are kindly being asked to participate because of your negative online experience while living with a long-term condition. Participation involves an interview taking approximately 30 minutes. Please read this information sheet and ask any questions.

What will the interview involve?

Interview questions will be related to your long-term condition and your experience with online harassment. The interview structure is not strict and you will be allowed to talk freely about your experience. If you agree to participate please contact the research team to arrange a convenient time and place or Skype interview. No preparation is required for the interview.

Do I have to take part?

No, participation is voluntary. You will be given the choice to not answer any question you are not comfortable to talk about, and you can withdraw from the study at any point without giving any reasons.

Confidentiality

All interviews will be strictly confidential and anonymous in accordance with the Data Protection Act 1998. Only the research team will have access to your information.

What will happen to the information I give?

The information you provide will be summarised anonymously in a group report that will be shared with the research team at the National Centre for Cyberstalking Research and will be used in academic publications with no means to be traced to your identity. Findings will be used to increase the awareness on online harassment impact on the health of patients and improve the support for victims.

How do I contact the researchers?

If you are interested in further information or if you want to complain please contact the research team at: nccr@beds.ac.uk

Appendix 15: Piloting the survey

Chronic Diseases Self-management and the Experience of Cyberstalking in the United Kingdom

Piloting the questionnaire

Once formal ethical permission was granted (appendix 1) a pilot study was conducted by the researcher in an overall duration of 4 weeks before commencing the main study. It is necessary to document clearly the methodology and lessons learned from the pilot survey to draw on for the main study and to share lessons with researchers in the field (van Teijlingen et al., 2001). The main aim of this pilot survey was to test the functionality, clarity and usability of the online questionnaire to make appropriate changes based on feedback before launching the main questionnaire. This section describes how the pilot study is conducted, feedback from the respondents and the lessons learned.

The importance of piloting

Piloting a questionnaire is to test it with a small number of people prior to conducting the main study (Seale, 2012). It is a small scale study using the full functioning tool to test whether it is working smoothly, and it should have a clear aim and to be reported clearly (Arain et al., 2010). Piloting could be done in various methods such as pretesting with colleagues, in-depth interviews or group discussions with the target population, or feedback from experts in the field (Bowling, 2009). It is recommended to pilot the questionnaire with people who have the same criteria as the target population in the main study (Boynton, 2004). When this is not possible then other few people such as colleagues and friends can be approached (Seale, 2012).

The benefits of piloting a questionnaire are uncovering unanticipated problems in the tool such as the language or words used, clarity of instructions, and how understandable the questions are (Seale, 2012). It also helps to calculate the average time spent to complete it, to discard any extra question that may not generate data but can make the questionnaire tedious to participants (Boynton, 2004). Rigorous piloting of a questionnaire is documented to improve response rate (Puleo et al., 2002) and maximising the chances of success of the main study (van Teijlingen and Hundley, 2001).

Factors that contribute to survey failure in achieving its aim include a tiresome questionnaire, uninteresting or boring layout, offending statements or ambiguous questions (Keeter et al., 2002; Boynton, 2004). Recruitment strategy could also be influenced by findings from piloting such as communication method or reliance on gatekeepers (Tolonen et al., 2015). Another issue to address is that participants and researchers may understand questions in different ways which can be an issue especially in health-related questions because it could

influence findings (Bowling, 2009). Accordingly, this pilot study was necessary to increase chances of success of the main study.

Procedures

The final draft of the questionnaire was first discussed with experts in cyberstalking and health research. After gaining ethical approval (appendix 1) the researcher used Qualtrics online platform to put the questionnaire online. This platform was chosen because of practical issues related to University's existing subscription and the availability of convenient questions' designs in Qualtric's library. The process of designing the questionnaire online included several tests to check the layout, question designs and navigation between sections. A further check was done to ensure that results reports reflect the main statistical output expected from each question. When the researcher was confident that the tool was ready to use a fully functioning pilot version of the questionnaire was launched.

It is recommended to clearly state to participants upon inviting them that this is a pilot survey (Bowling, 2009). Accordingly, the researcher explained to respondents that this is a pilot study and invited them to fill the questionnaire using ''think aloud'' approach. "Think aloud" means asking participants to think loudly while completing a task to get their real-time feedback on survey questions or use which helps in minimising memorising issues by participants (Collins, 2003; van Den Haak, De Jong and Jan Schellens, 2003).

Respondents provided concurrent feedback about each question while filling it, meanwhile, the researcher was observing respondents reactions to questions and monitoring time spent to complete the full version of the online questionnaire. After filling the questionnaire a short interview was conducted with a pre-designed set of questions derived from the literature (Seale, 2012; van Teijlingen et al., 2001; Bowling, 2009; Boynton, 2004). The set of questions covered the following points:

- Duration to complete the questionnaire
- Clarity of instructions
- Clarity of layout
- Confusing questions
- Objectionable questions
- Any additional comments to improve the questionnaire.
- Piloting questions are shown in the box below:

The Self-management of Chronic Conditions and the Experience of Cyber-victimisation in the United Kingdom

Survey piloting

- Please refer to the link in your email and kindly administer the questionnaire.
- Please answer the following questions with regards to the questionnaire you filled:

1. **How long did it take you to complete the questionnaire?**
2. **Were the instructions clear? (If no, please explain)**
3. **Was the layout clear? (If no, please explain)**
4. **Was there any confusing question? (if yes, please specify which one and why)**
5. **Was there any objectionable question? (if yes, please specify which one and why)**
6. **If you have further comments to improve the questionnaire please write it down. (Or communicate directly with the researcher)**

Some respondents preferred to receive the questionnaire via email. Based on their preference the researcher sent an email thanking them for their participation and explaining two steps, the first step was asking them to follow the link to the online questionnaire and fill it. The second step was asking them to answer a set of questions provided in a separate document after filling the questionnaire, or contact the researcher directly via email, phone, Skype or arranging a meeting to discuss feedback.

Respondents

The pilot study was done in two stages, the first stage included approaching people randomly on University campus in two locations, postgraduate centre and campus centre, to get general feedback. The second stage included targeting professionals in the field of healthcare and chronic diseases research via email invitations due to their active engagement with the chronically ill patients which is the target population.

The total number of respondents was 10 representing various demographics in age, gender, ethnicity and occupation. Four of them identified themselves as having long-term illnesses, and two of these went through the experience of cyberstalking/online harassment and provided answers and feedback based on their lived experiences. Respondents who do not have chronic illnesses were given the chance to take several attempts of the questionnaire and provide different answers to give feedback on the clarity of questions and layout.

Table (1) Demographic description of respondents who participated in the pilot survey

Demographic description	Frequency (n=10)
Gender	Female 90% Male 10%
Ethnicity	White English 60% African 30% Other 10%
Disability	Yes 10% No 90%
Age	19-43 years (mean 30.9)
Religion	No religion 40% Christian 50% Muslim 10%
Sexual orientation	Heterosexual 90% Gay/lesbian 10%
Area of residence	England 100% (40% Bedfordshire , 20% Buckinghamshire , 20% London, 10% East Sussex, 10% other)
Occupation	Manager 10% Sales worker 10% Professional 50% Other 30%

Lessons learned from piloting the questionnaire

Time to fill the questionnaire

The mean time spent to fill the questionnaire was approximately 15 minutes if answering all sections with no objection from respondents on the length of the questionnaire. Hence, no major change was done to the number or length of questions.

Recruitment

Approaching people randomly was not an effective method for several possible reasons 1) the pilot study was conducted on University campus during summer time which limited the potential number of respondents, 2) individuals with chronic conditions is limited in this context and 3) the majority of informative feedback came from respondents who preferred receiving the questionnaire link via email and provide non-verbal feedback. These issues are in the favour of online recruitment and targeting patient support groups to reach eligible participants.

Pre-screen

The main input from was moving question 11 (Q11) which is screening question about having a chronic illness to the pre-screen in the beginning of the questionnaire because many respondents start filling demographic data but they were not actually included in the study because they did not have chronic illnesses.

Layout

- In the consent page, one respondent asked for highlighting the statement before tick boxes.
- Some confusion was reported from respondents who thought they did not have to fill online harassment section, section C. Respondents who did not identify themselves as online harassment victims based on their response to Q18, yet their responses showed that they lie into online harassment category but were not aware of this experience based on their response in Q19 showed this confusion. Hence a connecting statement was added between the two questions.
- The skip logic after Q22 was changed and further tested, a technical issue was faced and required technical support from Qualtrics team.

Changes to questions

- "Prefer not to say" option was added to religion Q5.
- Further explanation was added to Q13 to write down the condition of most concern.
- The wording of one option in Q16 was changed, the change was from "It was expected/ or had no fear or distress" to "had no fear or distress" because one respondent highlighted that an illness could be expected but cause significant fear.
- Q18 asks about self-reporting of online harassment, one respondent thought it was too early to give a text box on this question because it is a sensitive issue. Accordingly, this box was changed to be optional.
- More details were added to Q22 by adding phone calls and detailing email option into personal and work email.
- The word "overall" was added to Q23.

Additional comments

Two respondents enquired why enlisting a question about disability Q3, and a question about chronic conditions Q13. The researcher revised disability definition in Equality Act 2010 (Equality Act 2010 Chapter 15) and disability discrimination act 1995 defining disability as "physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities''(Disability Discrimination Act 1995 Chapter 50. P.1), which covers some but not all chronic conditions included in this study hence no further amendments were made to these questions but a careful explanation will be included in discussing findings in section 4.4.

How the questionnaire reflected the aim of the study

Testing whether the questionnaire is giving useful data was promising. The two respondents who were actually having a chronic illness and experienced online harassment/cyberstalking were very keen to know more about the study, they showed interest and gave detailed feedback. Participants who experienced online harassment reported lower self-efficacy after experiencing online harassment which affected their management plan and directly related to the research question on the exploration of cyberstalking impact on chronic diseases self-management. Further details of individual responses are described below.

Respondent (x) was very cautious and did not submit the questionnaire until discussed anonymity, confidentiality and withdrawal with the researcher first. The respondent has a chronic condition for one year and experienced online harassment by ex-partner which caused extreme distress. Health efficacy scale for chronic disease self-management decreased from 7.3 before the experience of online harassment to 3.7 after experiencing online harassment, which feeds into the research question about the impact on self-management. Despite having regular appointments with the GP the respondent preferred including police and was not sure whether it has stopped. Further discussion and interest in the study were showed by the respondent.

Respondent (y) has a chronic condition with 5-10 years duration. The respondent experienced online harassment in online health forum by a stranger pretending to have the same condition to get more personal information. Health efficacy scale for chronic disease self-management decreased from 8.3 before the experience of online harassment to 7.7 after experiencing online harassment. Respondent's attitude toward GP was blaming the GP for being harassed in the first place because the respondent perceived that if the GP provided enough medical information during the consultation the respondent would not have looked for online forums. This response resulted in a long back and forth discussion between the researcher and the respondent about the aim of the study, disability definition and the influence of stress resulting from having a chronic illness on the findings, which may indicate the importance of using biographical disruption model to theorise data because it is accountable to stress inflicted by the chronic illness (Bury, 1982) and its complications (Larsson and Grassman, 2012), as discussed in section 2.5.2.

Respondent (z) has a long-term condition but did not experience online harassment. However the respondent was keen to give feedback and challenged the researcher about the importance of listing chronic acne in the list of conditions, supporting this by a link to a media campaign documenting the impact of online harassment on people having chronic acne because of their look resulting in significant impact on their daily living (BBC News, 2015).

Summary

This section reported how the researcher has piloted the questionnaire and outlines the lessons learned from this piloting stage. Minor changes were applied to layout, wording and order of questions. Data generated reflected that the questionnaire was understood and producing useful data relevant to the main aim of this stage of the study which is related to the extent and impact of online harassment on individuals living with chronic conditions. The next section describes launching the questionnaire in the main study.

Appendix 16: False victimisation

Table: Screening question to identify false victims

False victims	Screening	Questions to ask
Delusional (delusional disorder or Schizophrenia) (70% of cases)	***Screen for psychosis*** ○ Delusions of reference ○ Persecutory delusions ○ Delusions of control ○ Thought insertion, withdrawal or broadcasting ○ Auditory hallucinations **Auditory hallucinations in schizophrenia (commentary voices and thought echo)	❖ When you watch TV or read news do you ever feel that the stories refer to you directly, or to things you have been doing? ❖ Do you ever feel that people are trying to harm you or conspire against you in any way? ❖ Do you ever feel that people are paying special attention to you or talking about you behind your back? ❖ Do you ever get the feeling that others can read your thoughts or interfere with them? ❖ Do you ever get the feeling that you are being controlled? ❖ Do you feel If you have the chance you will do things that benefit humanity ❖ Have you ever experienced any visions, or smells that others didn't notice? ❖ Do you ever hear voices other people do not seem to hear? **Do you ever hear voices commenting on what you are doing or discussing you ong themselves? Or repeating your thoughts back to you?
False re-victimisation	History of victimisation (possibility of underlying PTSD or GAD)	❖ Have you ever experienced stalking or harassment before this incident? ❖ Have you ever experienced or witnessed a traumatic experience in your life?
Role reversal	(Possibility of underlying Narcissistic PD)	❖ Do you get the feeling that you are better than most of the people?

		❖ You mentioned that you know your stalker, can you please elaborate more on your relationship?
Factitious or Malingerer (sick role)	Elaborate more on illness **Or consider** **Hypochondriacal delusions	❖ You mentioned having an illness without being treated, can you please explain? (your symptoms, who diagnosed you, why are you not being treated? **Do you ever worry that there is anything wrong with your body or that you have a serious illness?
Differences between real and false victims	Demographics and history taking. ***False victims tend to be*** ○ Older age (50+) ○ No stable relationship ○ Unemployment history of traumatic experience ○ History of past victimisation ○ Shorter duration until reporting stalking ○ Longer duration of stalking (more than 5 years) ○ History of overuse of legal and medical services ○ Higher suicidal ideation	❖ What is your age? ❖ Are you currently in a long-term relationship? ❖ Are you currently employed? ❖ What was the duration until you recognised you are being stalked? ❖ Did your stalker threaten you to harm people around you or actually harmed them? (such as family or friends) ❖ You mentioned legal persuasion of services, how many times did approach legal services in the past years? ❖ You mentioned stalking impact on your wellbeing, how many visits you made to healthcare professionals complaining of this in the past years?

This screening was developed following expert opinion from Prof. Jim Barnes and Dr. Emma Short, and the following resources:

Bebbington, Paul, and Tony Nayani. "The psychosis screening questionnaire." International Journal of Methods in Psychiatric Research (1995).

Path, M., PAUL E. Mullen, and R. O. S. E. M. A. R. Y. Purcell. "Stalking: false claims of victimisation." The British Journal of Psychiatry 174.2 (1999): 170-172.

Semple, David, and Roger Smyth. Oxford handbook of psychiatry. Oxford University Press, 2008.

Sheridan, Lorraine P., and Eric Blaauw. "Characteristics of false stalking reports." Criminal justice and behavior 31.1 (2004): 55-72.

Appendix 17: Piloting the interview guide

The Self-management of Chronic Conditions and the Experience of Cyber-victimisation in the United Kingdom

Interview guide piloting

The interview guide was piloted in two stages:

Step 1: input from phase one

This step included piloting with one gatekeeper, who was also having a chronic condition and a victim of cyber-harassment. The gatekeeper suggested that the emotional impact should be further explored during the interview, this note was addressed in Q6.

Step 2: Input from experts in the field

The interview guide was developed following a discussion with experts in the field of cyber abuse and public health. It was further piloted with two healthcare researchers. The discussion resulted in the following changes:

- Make sure that the participant understands the right to withdraw by asking specifically on this after researcher's introduction.
- Q2 prompts were rearranged in a chronological manner.
- Q3 terminology was tailored to each specific case i.e cyberstalking or cyber-harassment to avoid confusing participants.
- Q4 a prompt was added 'what did you do next?'
- Make sure to provide contacts for support.

Appendix 18: Recruitment

Patient support groups

Number	Agreed	Declined	No response
1	○		
2	○		
3	○		
4			○
5	○		
6		○ No capacity	
7		○ Only their projects	
8			○
9		○ Data protection	
10		○ No capacity/illness	
11	○		
12	○		
13	○		
14	○		
15		○ No capacity	
16		○ Protect members (mental capacity)	
17	○		
18		○	
19	○		
20	○		
21			○
22	○		
23		○ Data protection	
24			○
25			○
26			○
27			○
28	○		
29			○
30			○
31	○		
32		○ Suggested partners because no direct contact with patients	
33		○ No capacity	
34	○		
35	○		
36			○
37			○
38			○

39	○		
40	○		
41			○
42		○ unable now	
43	○		
44	○		
45	○		

Victim support groups

Number	Agreed	Declined	No response/pending
1	○		
2	○		
3	○		
4	○		
5	○		
6	○		
7	○		
8	○		
9	○		
10	○		
11	○		
12	○		
13	○		
14	○		
15	○		
16	○		
17	○		
18			○
19	○		
20	○		
21	○		
22	○		

Individual gatekeepers or others

Number	Agreed	Declined	Pending
1	○		
2	○		
3			○
4			○
5	○		
6	○		
7	○		
8	○		
9	○		

10			
11			
12		Under 18	
13			
14			
15			
16			

GP recruitment

Number	Agreed	Declined	No response/pending
1			
2			
3			
4			
5			
6	Good response		
7	Hostility		
8	Only internally due to data protection		
9			
10			
11		Work for capita	
12		Audience	
13			
14			
15		Don't do any patient facing services	
16			

Appendix 19: Piloting the questions for GPs

The Self-management of Chronic Conditions and the Experience of Cyber-victimisation in the United Kingdom

GP- Written Interviews Piloting

The interview questions were put online and piloted before the launch of the main link. Piloting phase was in three steps.

Step 1: input from phase one

The first step was by informing the interview by information from the systematic review and phase one. The word cyber-victimisation was used to replace cyberstalking to avoid miscommunication. By examining the responses from patients who filled the survey in phase one, the answers suggested that victims are usually ashamed and embarrassed, and doctors had nothing to do with it. Accordingly, three questions were added:

- Q2c: How did cyber-victimisation come up during the consultation?
- Q3: What is your general opinion on the seriousness of cyber-victimisation impact on patients living with long-term conditions/disabilities?
- The former Q3 on clinical experience was merged with Q4 on the medical background knowledge.

Step 2: Input from experts in the field

The pilot-link was shared with one GP and two healthcare professionals, they were asked to go through the questions and then fill the piloting form:

- Please consider that respondents will be qualified doctors working in primary care.
    a. How long did it take you to write all your responses?
    b. Were the instructions clear? (If no, please explain)
    c. Was the layout clear? (If no, please explain)
    d. Was there any potentially confusing question to doctors? (if yes, please specify which one and why)
    e. Was there any objectionable question? (if yes, please specify which one and why)

The questions to 2-10 minutes to answer, and the following changes were made:

- Delete religion question in Section A on demographics because it was perceived offensive.
- Change the format of ethnicity question to a drop list to avoid giving a long question impression. This is because GPs are usually very busy.
- A typing error was corrected in the consent form.
- Remove ''the level'' of seriousness (quantitative)
- Revised the clarity of definition in Q1 and use the term cyber-victimisation because GPs respond to cyberstalking and cyberbullying differently.

Step 3: ICT input

The final version of the interviews was checked with an ICT expert. The following changes were made:

- Free text box sizes were enlarged
- Progress indicator was added
- Back button was added
- Consent functions were not working and were fixed

Appendix 20: GP questions

The Self-management of Chronic Conditions and the Experience of Cyber-victimisation in the United Kingdom

Short written interviews with GP

Eligibility criteria

Are you a General Practitioner (GP)?

Yes → Continue

No → Thank you, unfortunately, you are ineligible to participate in our study.

Have you ever worked as a GP in the UK?

Yes → continue

No → Thank you, unfortunately, you are ineligible to participate in our study.

General information and guidance

In this study, we aim to explore the impact of cyber-victimisation on patients living with chronic conditions or disabilities. The victimisation of people with long-term conditions is a documented phenomenon including harassment, bullying, stalking or disability hate crimes. It is documented that General Practitioners (GPs) are one of the first line professionals approached by victims. In this questionnaire we are interested to understand the experiences of GPs with patients with chronic diseases and being victims of harassment online, and how do GPs perceive the effects of such experiences on self-management plan.

This written interview is voluntary, if you start answering and feel that you do not want to complete it, you are absolutely free to withdraw at any point. Please do not provide personal information that can be traced to your patients' identities.

The interview consists of 7-10 short answer questions, covering demographic information and your experience with your patients who have chronic illnesses or disabilities. Please note that ALL your answers will be completely anonymous and will be kept confidential with no means that can be traced to your identity. Responses will be analysed and group results

will be reported to the National Centre for Cyberstalking Research (NCCR) at the University of Bedfordshire. Findings will be used to increase the awareness on cyber victimisation impact on health and improve the support for victims.

I confirm that I have read and understood the above information. ☐

I understand that my participation is voluntary and anonymous and that I am free to withdraw at any time without giving any reason. ☐

I agree to take part in the above study ☐

Contact details

If you are interested in further information or to complain please contact: nccr@beds.ac.uk

Section A: Demographic information, please specify the following:

Gender …….

Age in years ……

Ethnic background ……..

Religion ……..

Years of clinical experience ……..

Are you currently working as a GP? ……..

If yes, which county? …….

Section B: Your experience with cyber-victimisation

1. In this study we define cyber-victimisation as:
''Negative online experiences characterised by repeated unwanted contact via the Internet/electronic communication such as email, chatroom, online forum, social network, phone message or call, that causes fear or distress''.
Unwanted contact includes online/cyber harassment, cyberstalking, online trolling, cyber bullying, online discrimination or online disability hate incidents.

Have you ever encountered a patient with chronic disease or disability who was complaining of such negative online experiences?

Yes
No --> Please go to question 5

1. **If yes, pleases give more details on this encounter?**
   An approximate number of patients complained of cyberstalking/online harassment
   ……
   Presenting complaints ……..
   Advice given …….
   Please provide as much information as you can on your experience with these patients
   ……..……
   ……..……
   ……..
   ……
   ……..……
   ……..

2. **From your <u>clinical experience</u>, how does cyberstalking affect the self-management plan of patients with chronic conditions?**
   ……..……
   ……..……
   ……..
   ……
   ……..……
   ……..

3. **From your <u>background medical knowledge</u>, how does cyberstalking affect patients living with chronic conditions?**
   ……..……
   ……..……
   ……..
   ……
   ……..……
   ……..

4. **Have you ever directed your patients to an online health forum or online patient support groups?**
   Yes
   No --> Please go to question 8

5. **What was the experience of your patients with online health forums or online patient support groups? (Please provide details on positive and/or negative feedback communicated to you by your patients)**

   ……
   ……
   ……
   ……
   ……
   ……

6. **Would you like to add anything related to cyber-victimisation and chronic diseases?**

   ……
   ……
   ……
   ……
   ……
   ……

Contact details

We may need to contact you to clarify some of your answers, please provide your contact email (optional) ……
If you are interested in the findings of this study, or for further information please contact us using the contact email: nccr@beds.ac.uk

Your participation is appreciated!

Appendix 21: Codebook

Code label: Cyber-victimisation process

Colour: Navy blue

Short definition: Descriptions of the experience and/or the harasser

Full definition: This code covers the patterns described by the victims on the victimisation process and their perceptions on their harassers' attitudes. It also covers any explanations related to the victimisation experience such as the methods used and harasser's motivation.

When to use: Apply this code on victim's description on how the victimisation process started, perceptions around victimisation, motivation, methods used, and victims' portrayals of the harasser/harassers.

When not to use: When the process involves the social network of the victim or when the perception is hate-related.

Relevance to the research question: Relation to medical information, motivation and online support groups.

****Relation to hate code***

Code label: Prioritisation

Colour: Dark green

Short definition: Self-management importance during victimisation

Full definition: This code covers victims' accounts on the importance of the self-management of chronic conditions while being cyber-victimised.

When to use: Apply this code when the victim refers to managing the health condition during the experience of cyber-victimisation, or when the victim focuses on cyber-victimisation as a priority or distraction from health management.

When not to use: When the victim describes specific changes to health management.

Relevance to the research question: Adherence to self-management during victimisation.

****Relation to self-management code***

Code label: Disruption by condition

Colour: Orange

Short definition: Reaction to diagnosis and coping

Full definition: This code indicates victim's responses when asked about their reactions to the diagnosis of the chronic condition, and their subsequent coping. It examines coping in relation to biographical disruption.

When to use: Apply this code when the victim describes the reaction to the diagnosis, or having the condition at very young age, in addition to the implications of diagnosis on the victim's life and wellbeing before being cyber-victimised.

When not to use: When the victim describes health complications after being victimised.

Relevance to the research question: Examining the biographical disruption before victimisation.

**** Relation to existing complications code***

Code label: Existing self-management

Colour: Bright pink

Short definition: The self-management of chronic condition and follow up

Full definition: This code covers the specific aspects of the self-management of chronic conditions shared by the participants. It also addresses the implementation of this plan, relation to the surrounding culture and follow up.

When to use: Apply this code when the victim refers to the pharmacological or non-pharmacological management of health, any acceptance or struggle in implementing the plan. The consequences of carrying out the plan and follow up.

When not to use: When the victim describes the self-management of chronic condition after experiencing cyber-victimisation.

Relevance to the research question: Coping and cultural influence on self-management during victimisation

**** Relation to chronic conditions code, and to disability-hate code.***

Code label: GP

Colour: Yellow

Short definition: The role of GPs in shaping patient/victim experiences

Full definition: This code covers the role of GPs described by the participants through diagnosis, follow up, compassion, trust building and referrals. It applies to all stages of victimisation process.

When to use: Apply this code when the victim mentions their GPs role in managing health, instances that GP can help or can not help with, doctor-patient relationship, and referrals.

When not to use: When the victim describes the role of other instrumental support channels.

Relevance to the research question: The role of GP to support patients before and after victimisation.

**** Relation to instrumental support code.***

Code label: Existing complications

Colour: Brown

Short definition: The development of health complications prior to victimisation.

Full definition: This code covers the progression of the chronic condition. It includes health complications and subsequent struggle shared by the participants in relation to their health conditions.

When to use: Apply this code when the patients mention developing specific health complications prior to victimisation that required further follow up or lifestyle changes to cope.

When not to use: When the victim describes health complications after victimisation.

Relevance to the research question: The stability of the health before victimisation.

**** Relation to existing self-management code.***

Code label: CV impact and disruption

Colour: Dark orange

Short definition: The multi-level disruption caused by cyber-victimisation.

Full definition: This code covers the consequences of cyber-victimisations on victims. It examines the changes in victim's lives following victimisation and whether the biographical disruption model applies.

When to use: Apply this code when the patients refer to the impact on communication, personal accounts, employment, home and other living circumstances.

When not to use: When the victim describes health or mental wellbeing complications.

Relevance to the research question: The level of disruption after victimisation.

**** Relation to other themes on impact.***

Code label: Social network

Colour: Light blue

Short definition: The role of victim's social network in the experience

Full definition: This code highlight the different aspects of social support, how the victim's social network is involved in the victimisation process and the implications of this.

When to use: Apply this code when the victim refers to telling family or friends about victimisation, any positive or negative support, or the use of the social network to get closer to the victim.

When not to use: When the victim describes the cyber-victimisation process.

Relevance to the research question: Examining social support influence on self-management.

**** Relation to other themes on impact and CV.***

Code label: Instrumental support

Colour: Light grey

Short definition: The instrumental support received following victimisation.

Full definition: This code indicates any formal support channel that was approached or mentioned by victims and the consequences of that.

When to use: Apply this code when the victim refers to police, healthcare support, victim support charities, technical support, legal remedies, and consequences.

When not to use: When the victim mentions social support.

Relevance to the research question: Examining the role of instrumental support in improving/worsening the situation.

**** Relation to informal support.***

Code label: Underestimation and safety

Colour: Purple

Short definition: The victim's first responses to being harassed

Full definition: This code highlights the victim's reaction to being harassed that ranges from underestimation to safety concerns.

When to use: Apply this code when the victim's responses to victimisation started with reasoning and underestimation, or when the response escalated at any point to safety concerns.

When not to use: When the victim describes health and mental consequences.

Relevance to the research question: Examining the impact of escalation on avoiding health complications.

**** Relation to psychological impact.***

Code label: Psychological impact

Colour: Red

Short definition: The impact of cyber-victimisation on mental wellbeing

Full definition: This code highlights any psychological or psychiatric impact on victim's well-being secondary to being cyber-victimised. This includes any shared feelings, symptoms, behaviours or diagnoses.

When to use: Apply this code when the victim describes any emotional or mental health status following cyber-victimisation. This also includes symptoms, behaviours, any formal mental health diagnosis following victimisation or changes to an existing mental health condition.

When not to use: When the victim describes an existing mental health condition without changes.

Relevance to the research question: CV impact on victims' wellbeing.

**** Relation to prioritisation.***

Code label: Changes to self-management

Colour: Pink

Short definition: Changes to the self-management of chronic condition following cyber-victimisation.

Full definition: This code indicates any perceived deviations in the health management plan shared by the victims. This include changes to adherence, follow up, lifestyle modifications or overall changes.

When to use: Apply this code when the victim describes changes to controlling the health conditions such as medications, testing, follow up or overall changes.

When not to use: When the victim describes biological or mental health consequences.

Relevance to the research question: CV direct impact on self-management.

**** Relation to biological and mental health impact.***

Code label: Helplessness

Colour: Dark grey

Short definition: Victim's being helpless and persuasion of out of the box solutions.

Full definition: This code highlights the points where the victims felt helpless and abandoned with no options to improve the situation. It also includes any additional actions they took to survive the experience.

When to use: Apply this code when the victim describes cyber-victimisation as an endless experience, perceptions that there is nothing can be done, or when the victim adopted a new approach to survive.

When not to use: When the victim mentions instrumental support.

Relevance to the research question: CV impact on wellbeing and victims' choices.

**** Relation to mental health impact.***

Code label: Biological impact

Colour: Green

Short definition: The impact of cyber-victimisation on physical wellbeing

Full definition: This code indicates any physical symptoms developed by the participants secondary to cyber-victimisation. This includes symptoms, deterioration in the health condition or lab tests, developing new conditions or overall ill health.

When to use: Apply this code when the victim mentions physical complaints, lab tests, general ill health or new diagnoses.

When not to use: Exclude direct psychological impact.

Relevance to the research question: CV impact on the chronic condition and wellbeing.

**** Relation to mental health impact.***

Code label: Complexity

Colour: Black

Short definition: The perceived complexity of specific situations

Full definition: This code highlights the aspects of the cyber-victimisation experience in which the victim focuses on specific situations that are perceived to make the case more difficult than other cases.

When to use: Apply this code when the victim refers to specific complicated situations related to work, diversity, home, mental state or the health condition itself.

When not to use: Exclude instrumental support.

Relevance to the research question: CV impact variable impact in each situation.

**** Relation to instrumental support.***

Code label: Disability

Colour: Underlined/ light blue

Short definition: Perceived disability-hate

Full definition: This code highlights the perceived discrimination by the victim and the relation of cyber-victimisation to disability.

When to use: Apply this code when the victim refers to disability hate, cultural influences and the link between hate and the health condition.

When not to use: Exclude disability benefits.

Relevance to the research question: The motivation of harassers and subsequent support.

**** Relation to disability benefits.***

Code label: Disability benefits

Colour: Underlined/ grey

Short definition: The relation between disability benefits and cyber-victimisation.

Full definition: This code indicates the perceived relation between claiming disability benefits and the experience of cyber-victimisation. It applies to the situation before, during, and after victimisation. In addition to any perceived link.

When to use: Apply this code on the instances where the victim mentions disability benefits, disability hotline, tax and government.

When not to use: Exclude disability hate speech.

Relevance to the research question: The impact of cyber-victimisation on the victim's living situation.

**** Relation to disability benefits.***

Appendix 22: Letter to gatekeepers

Letter/email to gatekeepers

Subject: Chronic Conditions and the Experience of Cyber-victimisation

Dear (patient support/victim support) team,

I am writing to you with regards to a new study exploring the impact of cyber-victimisation on individuals living with chronic conditions in the United Kingdom.

About the research

Chronic diseases and victimisation are two increasingly prevalent issues in the UK, both of which are related to poor health outcomes. I am studying the extent, impact, coping of chronically ill individuals with the experience of cyberstalking. Based on reviewing published literature and discussion with cyber abuse experts this was not studied before in any other country. The study consists of a quantitative phase using an online survey and a qualitative phase using semi-structured interviews with patients/victims and healthcare professionals.

How can you help?

Your support to this study will be invaluable. As an admin to this (patient support/victim support) website I am requesting your permission to invite your website members to take part in this study.

What will your members benefit?

Patients/victims are expected to benefit from sharing their experiences and perceive support by being listened to. Participants who agree to be interviewed in the second stage will be given practical advice and a free copy of the eBook “A Practical Guide to Coping with Cyberstalking” as an arrangement to deal with this experience. On the longer term, the findings will be used to increase the awareness on the impact of cyberstalking on chronic illnesses to reshape and improve support available to victims.

Was this study ethically approved?

Yes, the study was ethically approved by the Institute for Health Research Ethics Committee, University of Bedfordshire. Participation is voluntary and all the information will be kept confidential and anonymous, data will be processed in accordance with Data Protection Act 1998. Participants have the right to withdraw at any point without giving a reason.

What happens next?

I will be very grateful if you respond to this email and explain whether it is of your interest to provide your website members with this study information and questionnaire link.

I will be delighted to share further details about this study, if you are interested in further information or to complain please use the contact information below.

Best regards,

Dr Zhraa Alhaboby
Qualified medical doctor (MBBS), MSc International Primary Healthcare (QMUL)
Researcher at the Institute for Health Research (IHR), Visiting Lecturer at the Faculty of Health and Social Sciences, University of Bedfordshire, UK
Fellow of the higher Education Academy (FHEA), UK
NCCR@beds.ac.uk

Appendix 23: Disability and cyber-harassment paper

Journal: Disability and Society Publisher: Taylor and Francis Impact factor: 1.1

'The language is disgusting and they refer to my disability': The cyberharrasment of disabled people

Abstract

Disabled people face hostility and harassment in their sociocultural environment. The use of electronic-communications creates an online context that further reshape this discrimination. We explored the experiences of 19 disabled victims of cyberharrasment. Five themes emerged from the study: disability and health consequences, family involvement, misrepresentation of self, perceived complexity, and lack of awareness and expertise. Cyberharrasment incidents against disabled people were influenced by the pre-existing impairment, perceived hate-targeting, and perpetrators faking disability to get closer to victims online. Our findings highlight a growing issue requiring action and proper support.

Keywords: online harassment; cyberstalking; cyberbullying; chronic conditions; disability hate crime; victimisation

Complete citation: Alhaboby, Z.A., al-Khateeb, H.M., Barnes, J. and Short, E., 2016. 'The language is disgusting and they refer to my disability': the cyber-harassment of disabled people. Disability & Society, 31(8), pp.1138-1143.

Appendix 24: Instrumental support paper

Status: under review

Coping with Cyberstalking: Victim's Perceptions on Utilising Instrumental Support

Cyberstalking is a prevalent offence with devastating impact on victims. The aim of this paper is to examine victims' perceptions on utilising instrumental support channels to cope with cyberstalking experience and how could this support be improved. Mixed methods design was used capturing responses from 305 participants, 89.8% of them (n=274) identified themselves as victims of cyberstalking. We examined participants' perceptions on the utilisation of services: police, doctor, therapy, counselling, a stalking helpline, victim support organisations and informational charity for people affected by stalking. Police was utilised by 63.2% of participants, followed by 46.8% therapy, 38.5% doctor, 35% counselling and 23.2% contacted a stalking helpline. Therapy was significantly perceived to be the most helpful in improving the situation. Various themes emerged in relation to each support channel. We mapped the interactions between support channels and discussed our findings with reference to the concept of trust to identify perceived obstacles in approaching and/or utilising support and positive points to start with for improvements. We concluded that victims' needs to cope with cyberstalking experience are based on two main points 1) expected actions to stop the harassment and 2) support to cope with distress symptoms. To match these needs improvements in collaborations, referrals and coherent multi-agency work are required at different levels of instrumental support.

Keywords: online harassment, victimisation, cyberbullying, electronic communication, stalking

Appendix 25: Working with Bedfordshire police

Chronic Conditions, Disabilities and Cyber-Victimisation in the UK

October 2016

As part of a larger project, analysed and written by: Dr Zhraa Alhaboby

Introduction

The discrimination against people living with disabilities and chronic conditions is an ancient phenomenon (Quarmby, 2011). It can range from harassment incidents to disability hate crimes. In the UK, disability hate crime is defined by the Association of Chief Police Officers (ACPO) and the Crown Prosecution Service (CPS) as “Any criminal offence which is perceived, by the victim or any other person, to be motivated by a hostility or prejudice based on a person's disability or perceived disability” (Crown Prosecution Service, 2018a). Electronic communication has further reshaped these experiences which resulted into cyber-victimisation, such as cyber-harassment, cyber-bullying and cyberstalking cases. When these offences are perceived to be motivated by prejudice they could be categorised under disability hate incidents/crimes or cyber-disability hate incidents. Cyber-victimisation imposes a huge impact upon victims, with the Police being one of the most important instrumental support channels approached by victims. Despite the work to address disability hate crime in the UK (Emerson and Roulstone, 2014) and the Police role in sharing their experiences (Richardson et al., 2016), little work has been done to look at cyber-disability hate incidents in relation to both cyber-victimisation and offline victimization (Alhaboby et al., 2016). This report examines documented police cases, looking for the patterns of reporting and impact upon victims to guide future work to support chronically ill cyber-victims.

Aims

- To examine the scope and impact of disability-related cyber offences documented by Bedfordshire Police between July 1st 2014 and January 31st 2016.
- To provide recommendations to improve support to victims by the Police.

Objectives

To achieve this aim, the objectives in this report are:

- To situate disability hate crime among documented cyber-victimisation cases.
- To identify patterns and impact on victims across documented disability-related cyber offences.
- To contextualise cyber-victimisation of people with long-term conditions in relation to documented disability-related cyber offences.

Appendix 26: Health promotion-dissemination

Letter to gatekeepers:

Dear gatekeeper,

Thank you for your help in recruiting participants for the study on cyber-victimisation of people with long-term conditions and disabilities. The results from this study will be used to increase awareness on the scope and impact of this experience on the victims.

The results were summarised in a tool in a form of a poster and a booklet (attached) to be shared with the gatekeepers, participants and wider audience. This email is to kindly ask you for the following:

1- Your input as a supporter is invaluable to us, hence we are hoping that you have a look at the attached and provide us with input from your invaluable experience to improve it, such as:
    - What are the positive aspects of the poster/booklet?
    - What are the negative aspects/things to improve in the booklet/poster?
    - Please provide any further feedback (for e.g content)
    - Are you interested in receiving a copy of the finalised booklet and poster?
    - If we send you a copy of the final booklet and poster, will you share it with others to raise awareness (for example victims or volunteers)?

2- The last part of the poster/booklet provides the victims with contact information of supportive organisations or groups. If you are happy to share your contact with the victims please state that in the link above or via email. (Adding your name to the tool is to support victims, disseminate your hard work and is free of charge).

** Please do not share the attached tool as it is not in its final stage.

Should you have any further questions please get back to me.

Best regards,

Dr Zhraa Alhaboby

Qualified medical doctor (MBBS), MSs International primary healthcare (QMUL)

Visiting lecturer and researcher at the Institute for Health Research (IHR), and the National Centre for Cyberstalking Research (NCCR), University of Bedfordshire, UK

Fellow of the higher Education Academy (FHEA), UK

To participants:

Dear Participant

Thank you for sharing your cyber-victimisation experience with us. We have summarised the results in a tool in a form of a poster and a booklet (attached) to be shared with the supporters, organisations and wider audience. This email is to kindly ask you to look at the attached and provide feedback in the following anonymous link:

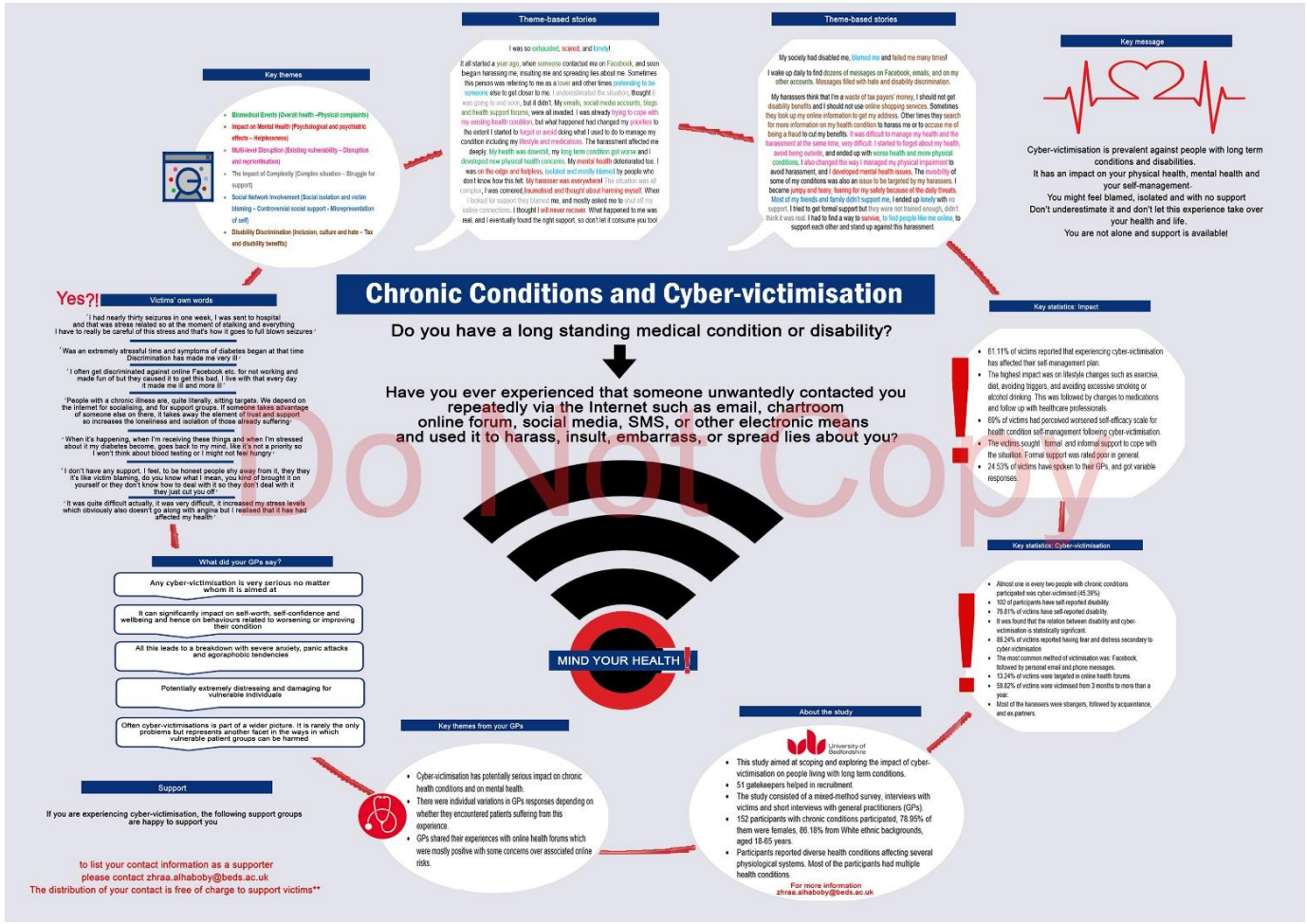
https://bedshealthsciences.eu.qualtrics.com/jfe/form/SV_9WxbvZFRSvq1kvb

As you are a partner in this work, your input will help to make sure that you experience was represented well, increase awareness among the public, use it to support other “victims”.

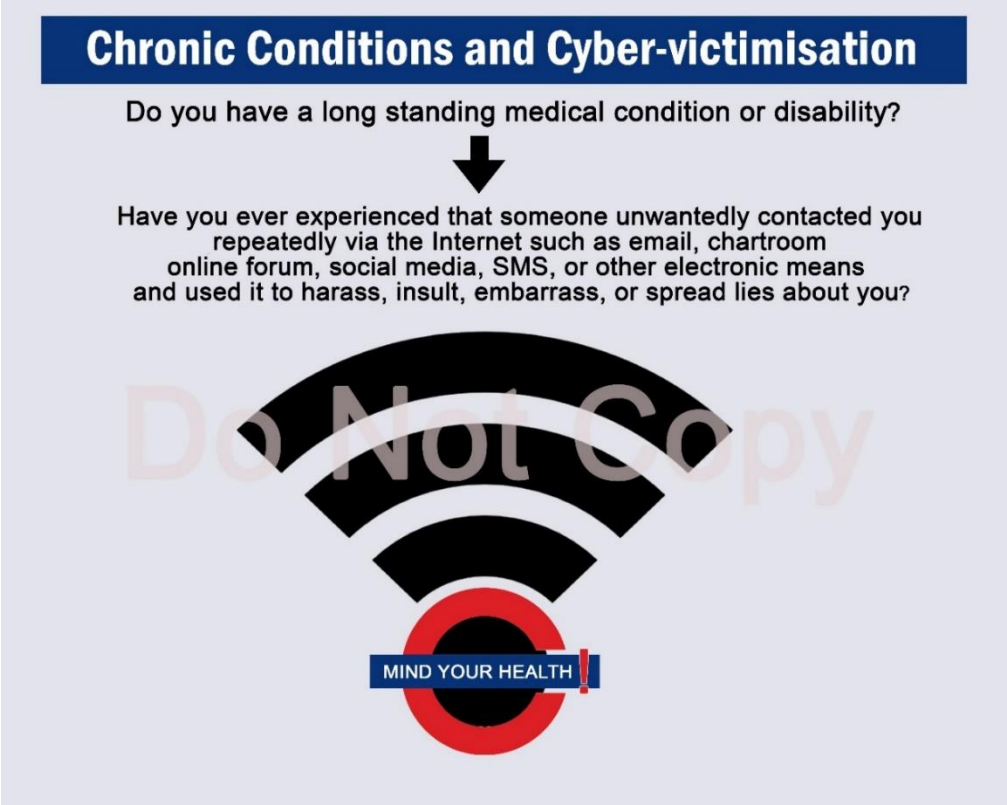
Thank you,

Dr Zhraa Alhaboby

Appendix 27: Health promotion poster –preliminary design



Appendix 28: Health promotion booklet –preliminary design



Theme-based stories

My society had disabled me, blamed me and failed me many times!

I wake up daily to find dozens of messages on Facebook, emails, and on my other accounts. Messages filled with hate and disability discrimination.

My harassers think that I'm a waste of tax payers' money, I should not get disability benefits and I should not use online shopping services. Sometimes they look up my online information to get my address. Other times they search for more information on my health condition to harass me or to accuse me of being a fraud to cut my benefits. It was difficult to manage my health and the harassment at the same time, very difficult. I started to forget about my health, avoid being outside, and ended up with worse health and more physical conditions. I also changed the way I managed my physical impairment to avoid harassment, and I developed mental health issues. The invisibility of some of my conditions was also an issue to be targeted by my harassers. I became jumpy and teary, fearing for my safety because of the daily threats. Most of my friends and family didn't support me, I ended up lonely with no support. I tried to get formal support but they were not trained enough, didn't think it was real. I had to find a way to survive, to find people like me online, to support each other and stand up against this harassment.

Key themes

- **Biomedical Events (Overall health –Physical complaints)**
- **Impact on Mental Health (Psychological and psychiatric effects – Helplessness)**
- **Multi-level Disruption (Existing vulnerability – Disruption and reprioritisation)**
- **The Impact of Complexity (Complex situation – Struggle for support)**
- **Social Network Involvement (Social isolation and victim blaming – Controversial social support - Misrepresentation of self)**
- **Disability Discrimination (Inclusion, culture and hate – Tax and disability benefits)**

Yes?! Victims' own words

'I had nearly thirty seizures in one week, I was sent to hospital and that was stress related so at the moment of stalking and everything I have to really be careful of this stress and that's how it goes to full blown seizures'

'Was an extremely stressful time and symptoms of diabetes began at that time Discrimination has made me very ill'

'I often get discriminated against online Facebook etc. for not working and made fun of but they caused it to get this bad, I live with that every day it made me ill and more ill'

'People with a chronic illness are, quite literally, sitting targets. We depend on the internet for socialising, and for support groups. If someone takes advantage of someone else on there, it takes away the element of trust and support so increases the loneliness and isolation of those already suffering'

'When it's happening, when I'm receiving these things and when I'm stressed about it my diabetes become, goes back to my mind, like it's not a priority so I won't think about blood testing or I might not feel hungry'

'I don't have any support. I feel, to be honest people shy away from it, they they it's like victim blaming, do you know what I mean, you kind of brought it on yourself or they don't know how to deal with it so they don't deal with it they just cut you off'

'It was quite difficult actually, it was very difficult, it increased my stress levels which obviously also doesn't go along with angina but I realised that it has had affected my health'

What did your GPs say?

Any cyber-victimisation is very serious no matter whom it is aimed at

It can significantly impact on self-worth, self-confidence and wellbeing and hence on behaviours related to worsening or improving their condition

All this leads to a breakdown with severe anxiety, panic attacks and agoraphobic tendencies

Potentially extremely distressing and damaging for vulnerable individuals

Often cyber-victimisations is part of a wider picture. It is rarely the only problems but represents another facet in the ways in which vulnerable patient groups can be harmed

Key themes from your GPs

- Cyber-victimisation has potentially serious impact on chronic health conditions and on mental health.
- There were individual variations in GPs responses depending on whether they encountered patients suffering from this experience.
- GPs shared their experiences with online health forums which were mostly positive with some concerns over associated online risks.

About the study

University of Bedfordshire

- This study aimed at scoping and exploring the impact of cyber-victimisation on people living with long term conditions.
- 51 gatekeepers helped in recruitment.
- The study consisted of a mixed-method survey, interviews with victims and short interviews with general practitioners (GPs).
- 152 participants with chronic conditions participated, 78.95% of them were females, 86.18% from White ethnic backgrounds, aged 18-65 years.
- Participants reported diverse health conditions affecting several physiological systems. Most of the participants had multiple health conditions.

For more information
zhraa.alhaboby@beds.ac.uk

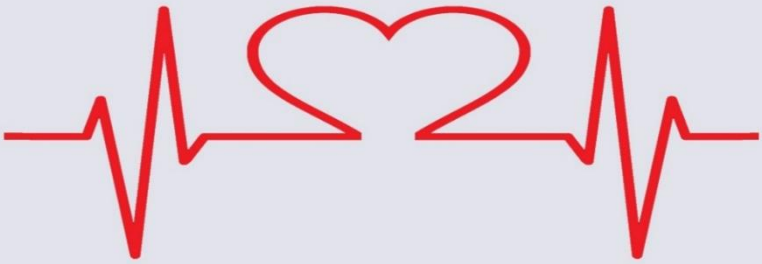
Key statistics: Cyber-victimisation

- Almost one in every two people with chronic conditions participated was cyber-victimised (45.39%)
- 102 of participants have self-reported disability.
- 76.81% of victims have self-reported disability.
- It was found that the relation between disability and cyber-victimisation is statistically significant.
- 88.24% of victims reported having fear and distress secondary to cyber-victimisation
- The most common method of victimisation was: Facebook, followed by personal email and phone messages.
- 13.24% of victims were targeted in online health forums.
- 58.82% of victims were victimised from 3 months to more than a year.
- Most of the harassers were strangers, followed by acquaintance, and ex-partners.

Key statistics: Impact

- 61.11% of victims reported that experiencing cyber-victimisation has affected their self-management plan.
- The highest impact was on lifestyle changes such as exercise, diet, avoiding triggers, and avoiding excessive smoking or alcohol drinking. This was followed by changes to medications and follow up with healthcare professionals.
- 69% of victims had perceived worsened self-efficacy scale for health condition self-management following cyber-victimisation.
- The victims sought informal and informal support to cope with the situation. Formal support was rated poor in general.
- 24.53% of victims have spoken to their GPs, and got variable responses.

Key message



Cyber-victimisation is prevalent against people with long term conditions and disabilities.
It has an impact on your physical health, mental health and your self-management.
You might feel blamed, isolated and with no support
Don't underestimate it and don't let this experience take over your health and life.
You are not alone and support is available!

Support

If you are experiencing cyber-victimisation, the following support groups are happy to support you

to list your contact information as a supporter
please contact zhraa.alhaboby@beds.ac.uk
The distribution of your contact is free of charge to support victims**

Appendix 29: Health promotion poster –revised design

Appendix 30: Health promotion booklet –revised design